SUPPLEMENT 10

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Racial Disparities in Cancer Care | Access to Care for Transgender Veterans | Hepatitis C Among US Veterans | Battling Tobacco Use at Home | HEALTH EQUITY | How Might the Provision of Culturally Competent Services Be Enhanced for American Indian and Alaska Native Veterans? | Improving Trends in Gender Disparities | Suicidality Among Hispanic and African American Veterans Following Surgery

APHA

To Save Lives, We Need to Improve the Measurement of Death

Public health's fundamental mandate is to protect and improve the human condition. It does so at the individual, community, and societal levels through efforts meant to enhance well-being; to reduce disease morbidity, disability, and injury; and to delay mortality. Reflecting the practical underpinnings of the field, measurements of these outcomes are woven into the scaffolding of extensive public health surveillance and administrative structures. Good measures both provide early warning signals for active intervention and serve as a scorecard for the effectiveness and equity of public health practices. They also allow comparative population-based approaches that might reveal new insights into the widespread effectiveness of policy changes and identify unrecognized or underappreciated, but hopefully modifiable, risk indicators.

Hence, in the field of public health there is an emphasis on using well-articulated approaches with known effectiveness and standardized reliable and valid measures of circumstances (e.g., the use of *International Classification of Diseases* codes to classify disease and cause of death). Of all these outcomes, that which may seem easiest to measure is death. But as described in many articles in this special issue, the COVID-19 pandemic unmasked smoldering concerns about the patchwork of mortality tracking in the United States and elsewhere (https://bit.ly/2RE5Agu). As has also been noted (https://bit.ly/2RE5Agu), COVID-19 mortality statistics are only as good as their timeliness and accuracy if they are to be used to inform decision-making.

Despite the epidemiological transition after World War II to a broader focus on chronic disease as the major source of human morbidity and mortality, emerging infectious diseases in subsequent decades, such as AIDS, H1N1, Ebola, and Zika, served to maintain investments in basic, behavioral, and clinical sciences; workforce development; and surveillance and tracking systems aimed at control of infectious disease. Thus, we were partially prepared for the emergence of COVID-19 and the rapid development of vaccines with which to combat it. But novel infectious diseases challenge existing systems to respond rapidly to change—the pandemic itself is evidence that our first-line measures of infection control were not up to the challenge. The second line of defense is control and mitigation. Here is where effective tracking of mortality can greatly contribute to identifying vulnerable populations, patterns of spread, vulnerabilities and social risk determinants of infection, effectiveness of clinical interventions, and emerging public health needs (https://bit.ly/3whXucc). With COVID-19, longstanding concerns related to classifying cause of death bubbled up (e.g., When is a cause coded as the underlying cause vs a contributing cause? Can the cause be determined by signs and symptoms, or does it require laboratory confirmation?).

As well, problems emerged with incomplete records or records completed by individuals overwhelmed with marshaling their resources for the needs of the living. Racial/ethnic status was missing in 48% of vaccine records in the first month of vaccinations although race/ethnicity is a major risk indicator in COVID-19 mortality (https://bit.ly/2Tc24tW). Political and family preferences to alter administrative death records for purposes other than accuracy and fundamental documentation issues (e.g., number of fields in an electronic death record, completion of death records by varied entities, deaths occurring in and out of hospital) also shaped the quality of the information that was logged (Aiken, p. S55; Bensimon, p. S57). Delays in compiling the information may have undercut the utility of mortality data for timely decision-making and prevention of new cases of infection. Finally, some approaches, such as reporting excess mortality, depend on assumptions about disease stability (https://bit.ly/2SbMKh7), which may be somewhat questionable in the context of widespread disruption in usual patterns of health care.

All these issues, raised in many articles in this special issue, affect the quality of our death records. The COVID-19 pandemic taught all of us many lessons. Hopefully one of these is the importance of a robust vital registry compiled with alacrity, greater standardization, accuracy, and completeness of data on individual risk indicators such as race and ethnicity (https://bit.ly/2RE5Agu). AJPH

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Nabarun Dasgupta, *AJPH* Associate Editor; Denys T. Lau, *AJPH* Associate Editor; Vickie M. Mays, Guest Editor; and Susan D. Cochran, Guest Editor, served as Editors for this supplement issue on "When Dying Really Counts: Mortality Data in Public Health Surveillance." As the lead *AJPH* Editor, N. Dasgupta identified reviewers, solicited manuscripts, commissioned cover art, and recommended which papers should be accepted or rejected. D. T. Lau identified reviewers and recommended which papers should be accepted or rejected. Suitability was determined by *AJPH* Editor-in-Chief Alfredo Morabia, N. Dasgupta, D. T. Lau, and V. M. Mays, collectively. V. M. Mays and S. D. Cochran conceptualized the supplemental issue and commissioned the editorials that focused on mortality data issues, experiences of first responders in handling death, policy implications of data inequities in COVID-19, and police-related deaths from shootings and in custody. V. M. Mays and S. D. Cochran authored the introduction to the supplement and also authored the Editor's Choice. N. Dasgupa wrote an editorial.

CONFLICTS OF INTEREST

Nabarun Dasgupta, PhD, MPH, has no conflicts of interest to disclose.

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A Look at When Dying Really Counts: An *AJPH* Supplement on Mortality Data in Public Health Surveillance

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Langston Hughes, a Black Harlem Renaissance writer remembered for his captivating stories of Black life, once wrote, "Life is for living. Death is for the dead. Let life be like music. And death a note unsaid." In this supplement, titled "When Dying Really Counts: Mortality Data in Public Health Surveillance," *AJPH* chooses not to follow Hughes's admonition. Instead, the special issue shares many notes about mortality—one of the two pillars in vital statistics—in an effort to reveal the vitality of this field. Three underlying themes crisscross the many articles and editorials included.

First, several authors underscore the need to improve the quality of mortality data and routine surveillance in general. This is true for disasters (Stoto et al., p. S93), when the world is experiencing a global pandemic (Penaia et al., p. S49; Stokes et al., p. S53; Aiken, p. S55; Bensimon, p. S57; Zimmermann et al., p. S59), and when we are trying to learn from mortality incidents to delay or reduce their occurrence (Aiken; Pathak et al., p. S101; Eisler and Smith, p. S63; Young et al., p. S65; Arseniev-Koehler et al., p. S107; Feldman and Bassett, p. S69; Palframan et al., p. S116; Galea and Ettman, p. S73). Throughout this issue, the case is made for better linkages to build a more robust system of tracking mortality (Cochran and Mays, p. S45).

Second, inaccuracies in mortality data have real consequences for the public health mission. The extensiveness of missing data or inaccurate classifications in race/ethnicity codes in clinical testing data, immunization registries for COVID vaccinations, health survey data (Small-Rodriguez and Akee, p. S126), and hospital and administrative data impairs the work of public health and marginalizes already challenged populations (e.g., racial/ethnic minorities, low-income individuals, and those living in rural areas [Hayes-Bautista et al., p. S133; Mays et al., p. S75]). For COVID-19–related deaths, the exigencies of the pandemic when combined with preexisting weaknesses in many mortality systems will continue to plague our abilities to quantify the ultimate impact of the pandemic (Stokes et al.).

Third, the public health professionals who register deaths, aid the bereaved, and conduct mortality research (Dasgupta, p. S80) in fidelity with those who have died comprise a unique public health resource. Funeral directors, coroners, and medical examiners play a critical role in recording deaths accurately and in providing an essential interface between medical systems, legal institutions, and families of the deceased. Like our doctors, nurses, emergency medical technicians, and others, these often unrecognized first responders found themselves especially challenged by the COVID-19 pandemic. In one article, we are reminded that there are those among us who want to know about death, be prepared for it, and come together for solace after a loved one dies. This has birthed an international movement of death cafés to allow the living to learn from each other and those who have died (Chang, p. S82).

Other articles in this issue convincingly make the point that there are solutions to mortality coding and measurement concerns that have been allowed to fester (Finlay and Genadek, p. S141; Ramchand et al., p. S84; Chandra and Christensen, p. S149). For example, Wojcik et al. (p. S156) ask that we not forget about studying the contributions of genetic disorders in infant mortality but also note that, to do so, *International Classification of Diseases* codes need to provide better capture of Mendelian monogenic disorders.

Stoto et al. provide insights into a proposed framework for mortality data capture during disasters and pandemics. These changes are long overdue. When Hurricane Katrina resulted in large numbers of deaths, our systems of managing mortality were not up to the challenge. Similar difficulties arose in Puerto Rico following Hurricane Maria. Efforts to document the death toll from that disaster bogged down in politics; it took lawsuits before there were serious efforts to count the losses on the island. Many authors offer creative fixes, such as tracking unregistered deaths through patterns of credit card use (Zimmermann et al.).

Probably the most compelling calls for macrosolutions come from Reverby (p. S89) and Krieger (p. S91). Reverby observes that if public health is not guided by a social justice approach, we may end up viewing the racial/ethnic health disparities of the COVID-19 pandemic as “normal.” Finally, Krieger calls for public health to step up to its responsibility for accurate, timely, and complete mortality statistics. She reminds us all that mortality is shaped by the sociopolitical context of current data limitations and contextual meanings of death.

We invite you to spend some time as well looking at the cover for this special issue—the illustrations seek to capture visually some of the themes covered. AJPH

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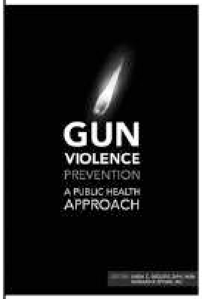

Disparities in Native Hawaiian and Pacific Islander COVID-19 Mortality: A Community-Driven Data Response

Corina S. Penaia, MPH, Brittany N. Morey, PhD, MPH, Karla B. Thomas, MPH, Richard C. Chang, JD, Vananh D. Tran, BA, Nicholas Pierson, MS, John Greer, MS, and Ninez A. Ponce, PhD, MPP

As of March 2021, Native Hawaiians and Pacific Islanders (NHPIs) in the United States have lost more than 800 lives to COVID-19—the highest per capita death rate in 18 of 20 US states reporting NHPI deaths. However, NHPI risks are overlooked in policy discussions. We discuss the NHPI COVID-19 Data Policy Lab and dashboard, featuring the disproportionate COVID-19 mortality burden for NHPIs. The Lab democratized NHPI data, developed community infrastructure and resources, and informed testing site and outreach policies related to health equity. (*Am J Public Health*. 2021;111(S2):S49–S52. https://doi.org/10.2105/AJPH.2021.306370)

Native Hawaiians and Pacific Islanders (NHPIs) experience some of the highest COVID-19 death rates of all racial and ethnic groups in the United States.[1,2]

INTERVENTION

At the UCLA Center for Health Policy Research, the NHPI COVID-19 Data Policy Lab (hereafter referred to as "the Lab") formed to support community data needs and has a close partnership between NHPI community leaders and researchers working to inform national, state, and local COVID-19 prevention efforts.

PLACE AND TIME

Early in the COVID-19 pandemic, reports from funeral homes, churches, and social networks on NHPIs getting sick and dying of COVID-19 sounded an alarm for community action. A coalition of community leaders and researchers known as the National Pacific Islander COVID-19 Response Team convened to protect NHPI health and expressed an urgent need for data infrastructure to support their efforts. This led to the formation of the Lab in partnership with the UCLA Center for Health Policy Research in March 2020. The Lab is powered by graduate students and working professionals, several of whom identify as NHPI. Within 5 months, the Lab responded to community guidance to generate data products and launch a NHPI COVID-19 online dashboard, revealing COVID-19 impacts on NHPIs across the United States. To our knowledge, this is the first time a research university in the continental United States committed resources to sustain a pipeline of NHPI researchers to meet the community's data needs.

PEOPLE

There are more than 1.2 million NHPIs in the United States, and they have a diverse set of cultures and languages. According to the Office of Management and Budget, NHPI is defined as a person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands in Polynesia, Melanesia, and Micronesia.[3]

High COVID-19 case and death rates among NHPIs are attributable to health and socioeconomic inequities that existed before COVID-19. NHPIs have disproportionately high rates of chronic diseases that are linked to increased risk of COVID-19, including heart disease, diabetes, and asthma.[4,5] As with other vulnerable communities, NHPIs have relatively high poverty and uninsurance rates.[5]

PURPOSE

The Lab's dashboard indicates that there are higher COVID-19 death rates among NHPIs than any other racial or ethnic group in 18 of 20 states reporting disaggregated NHPI death data. Figure 1 shows a total of 837 NHPI COVID-19

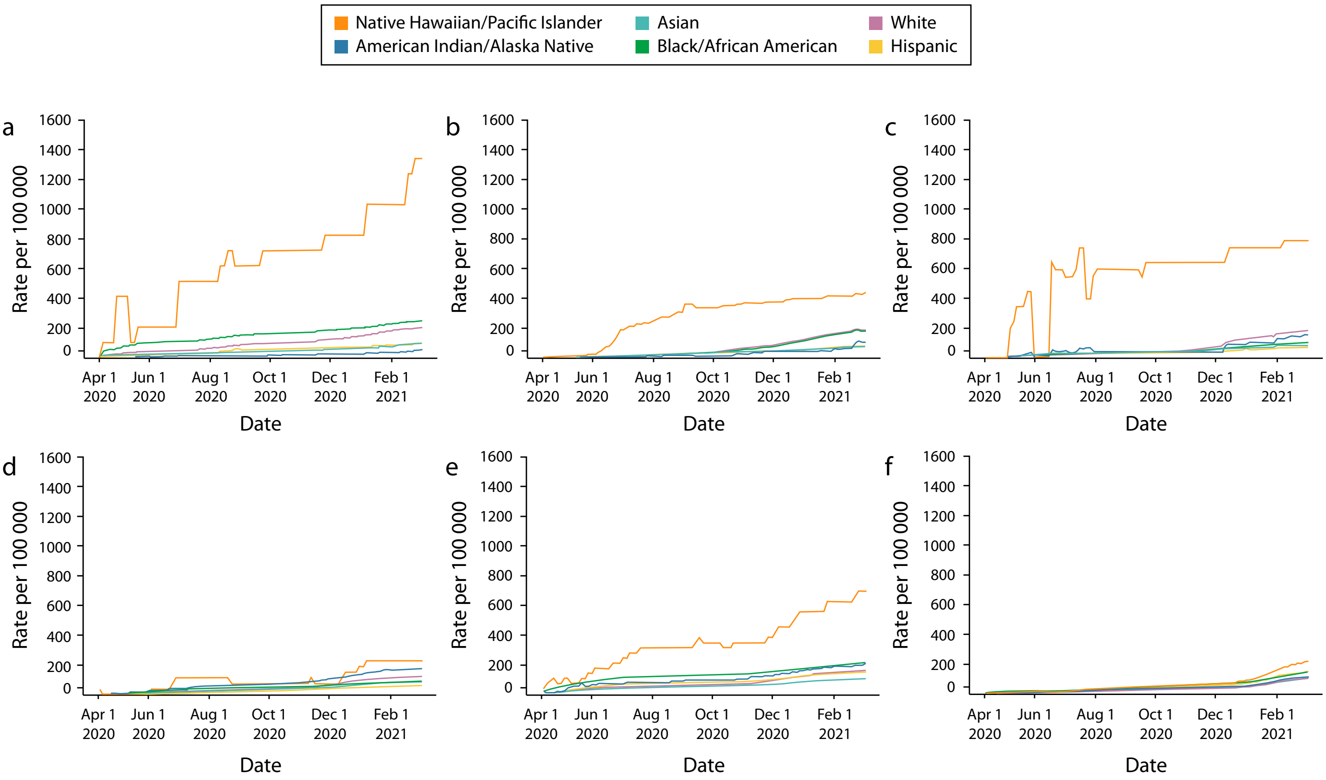

FIGURE 1— State Racial and Ethnic Death Rates per 100 000 as of March 3, 2021 in (a) Louisiana, (b) Arkansas, (c) Iowa, (d) Minnesota, (e) Illinois, and (f) California

Source. COVID Racial Data Tracker.[7] Last accessed March 4, 2021; US Census Bureau, 5-year American Community Survey, Table DP05.
Note. The Native Hawaiians and Pacific Islanders COVID-19 Data Policy Lab updated the population denominators for calculating case and death rates to use the 2019 American Community Survey 1-year population estimates. The updated calculations continue to match the different definitions of the race and ethnicity states use in their COVID-19 reporting.

deaths reported in the United States. The top 3 states with the highest number of NHPI COVID-19 deaths are California (311), Hawai'i (137), and Washington (80). Louisiana currently has the highest NHPI death rate (1338.83 per 100 000). Before the Lab's research and advocacy efforts, lack of timely reporting of NHPI disaggregated data curtailed public health program and community-based response efforts to address COVID-19 in the NHPI population.

The Office of Management and Budget mandate to provide NHPI disaggregated data in disease reporting holds health agencies accountable for releasing accurate racial and ethnic data. This allows NHPIs a voice in policy decision-making, including decisions regarding allocation of resources to address community health needs.

States lack uniformity for collecting and reporting NHPI disaggregated data; only 42% and 36% of states report NHPI disaggregated case data and death data, respectively.

IMPLEMENTATION

The Lab's methodology consisted of faculty researchers manually scraping case and death data from 11 online state and county COVID-19 dashboards as the National Pacific Islander COVID-19 Response Team requested. Researchers calculated case and death rates using the 2019 American Community Survey 1-year population denominators, matching the different tabulations of race and ethnicity on the state and county COVID-19 dashboards. Dashboards differed in reporting race as single race, alone, or in combination and in reporting ethnicity (i.e., Hispanic/Latino identification) with race together or separately.

In April 2020, graduate students and working professionals joined the Lab to increase its capacity for recording data and to automate this process using the programming language Python (Python Software Foundation, Wilmington, DE). By June 2020, the National Pacific Islander COVID-19 Response Team expanded its data requests to 32 states and counties.

To increase efficiency, in August 2020, the Lab shifted to the COVID Racial Data

Tracker Dashboard as a primary source of state-level data to calculate case and death rates, with population denominators aligned to each state's race/ethnicity tabulations of cases and deaths.[6]

The Lab developed an online dashboard in September 2020 featuring NHPI-specific national COVID-19 data, which includes state-level summaries, a US heat map, and line graphs of NHPI cases and deaths over time. The dashboard describes how states not disaggregating NHPI data treat the NHPI category: NHPIs aggregated with Asians, NHPIs aggregated under the "other race" category, or no explanation of how NHPIs are counted.

EVALUATION

Advocates have used the Lab's data to increase awareness of COVID-19 impacts on NHPIs and urge decision makers to support community-driven efforts. At least 10 regional Pacific Islander COVID-19 response teams and the National Pacific Islander COVID-19 Response Team rely on the Lab's dashboard data. The dashboard has been viewed more than 2300 times since it launched. These efforts have the potential to affect more than 1.2 million NHPIs living in the United States.

The Inland Empire Pacific Islander COVID-19 Response Team used the Lab's data to advocate disaggregated NHPI data in Riverside County, California. The county's improved data-reporting practices showed that NHPIs exhibit the highest COVID-19 case rate among all racial and ethnic groups. This motivated the health department to support the Inland Empire Pacific Islander COVID-19 Response Team with more than $60 000 to combat COVID-19 among NHPIs through interventions.

At the state level, the National Pacific Islander COVID-19 Response Team presented the Lab's research to advocate equitable COVID-19 action during a meeting with the director of the California Department of Public Health in September 2020, which resulted in the California Department of Public Health's commitment to prioritize NHPIs in California's COVID-19 efforts.

In September 2020, the Lab supported a national campaign demanding that the National Academies of Sciences, Engineering and Medicine include NHPIs in their plan for equitable allocation of the COVID-19 vaccine by sending in advocacy letters and providing public comments. These efforts advised the National Academies of Sciences, Engineering and Medicine's final vaccine plan, which recognized NHPIs as a priority population. On September 14, 2020, the Lab submitted video, dashboard, and research materials to the National Committee on Vital and Health Statistics Virtual Hearing on Privacy, Confidentiality and Security Considerations for Data Collection and Use during a Public Health Emergency.

ADVERSE EFFECTS

Because of the size of the NHPI population, public reporting of data is a privacy concern. Nevertheless, the vast NHPI health disparities and the deadly COVID-19 consequences suggest that arbitrary threshold requirements for reporting are barriers to prevention. We argue that NHPI data reporting, even when numbers are small, is necessary to inform swift action to protect populations. The long-standing lack of NHPI disaggregated data before the pandemic contributed to the underresourcing of the few organizations with the expertise to implement culturally competent COVID-19 programs.

SUSTAINABILITY

The investment of resources in community–academic partnerships such as the Lab would increase community capacity and resiliency to address the current COVID-19 pandemic and future health challenges. The Lab recently received support from the Robert Wood Johnson Foundation, which is recognized for its community-centered approach to improving public health data.

PUBLIC HEALTH SIGNIFICANCE

The Lab's accomplishments improve community efforts to democratize NHPI disaggregated data. This work demonstrates that community-engaged research is effective and ensures the completeness and appropriateness of public surveillance and action. We provide a model that is community driven, pipeline building, and scalable for other populations that are overlooked in public health data systems. AJPH

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C. S. Penaia, B. N. Morey, and K. B. Thomas conceptualized the study and performed the formal analysis and investigation. C. S. Penaia, K. B. Thomas, and R. C. Chang prepared the original draft of the article. R. C. Chang was responsible for the study methodology. All authors wrote, reviewed, and edited the article.

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The authors have no conflicts of interest to declare.

HUMAN PARTICIPANT PROTECTION

This research did not involve human participants, so institutional review board approval was not required.

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Excess Deaths During the COVID-19 Pandemic: Implications for US Death Investigation Systems

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Quality death investigation is a critical piece of an effective public health system.[1] When a person dies, a coroner, medical examiner, or health professional with knowledge of the decedent's medical conditions fills out the death certificate. Accurate cause-of-death ascertainment has broad implications for understanding the burden of disease throughout the United States.

During the coronavirus disease 2019 (COVID-19) pandemic, vital statistics have had an important role in shaping the public health response, including recommendations for physical distancing and mask wearing, temporary lockdowns, and mobilization of health care systems.[2] Racial and socioeconomic disparities in deaths attributed to COVID-19 have shown how structural racism contributed to vulnerability during the pandemic.[3]

Although monitoring death certificates for reference to COVID-19 is a useful method for detecting the mortality associated with severe acute respiratory syndrome coronavirus 2 infection, it is likely to result in an undercount if COVID-19 is missing on death certificates in cases in which COVID-19 contributed to death.[4–6] In fact, between 15% and 34% of excess deaths that occurred in 2020 during the COVID-19 pandemic were not directly assigned to COVID-19 on death certificates.[7] These deaths likely include COVID-19 deaths not assigned to COVID-19 and indirect deaths related to social and economic consequences of the pandemic.

Previous work has demonstrated that the percentage of excess deaths not assigned to COVID-19 varies by state and county.[4,6] At the county level, a previous analysis found that the percentage of excess deaths not assigned to COVID-19 was higher in areas with lower average socioeconomic status, counties with more non-Hispanic Black residents, and counties in the South and West.[6] Areas without medical examiners may also have a higher percentage of excess deaths not assigned to COVID-19.[8] Many of these areas rely on coroners who are laypeople who typically lack professional training in medical certification, are usually elected, and often serve dual roles such as a sheriff–coroner.[1]

One reason why COVID-19 deaths may not be assigned to COVID-19 is if testing does not occur. In rural areas, where coroners are more common, there is often less access to health care, including COVID-19 testing.[9] Coroners may also be less likely to perform postmortem COVID-19 testing as a result of budget limitations. Moreover, prior research has identified partisan differences in attitudes toward COVID-19 and behaviors such as physical distancing and mask wearing.[10] Thus, partisan differences could affect the likelihood that an individual or their family members seek COVID-19 testing while alive and whether coroners pursue postmortem testing. Because some states require testing for confirmation of a COVID-19 death, this could affect a state's COVID-19 death count.[11]

Regardless of the cause, the possibility that the quality of death investigation systems may affect the reporting of COVID-19 deaths holds implications for the study of geographic variation in COVID-19 mortality, which is an important tool for documenting disparities. If disparities in excess deaths not assigned to COVID-19 differ from disparities in deaths directly assigned to COVID-19, at-risk populations may be missed when monitoring assigned COVID-19 deaths alone. For this reason, when feasible, we believe excess mortality should be leveraged in studies of geographic and other population variation in COVID-19 mortality.

Moving forward, greater attention should be given to the death investigation system in the United States, including to potential data quality issues associated with the coroner system. As the case of COVID-19 demonstrates, differential ascertainment may be more

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likely when determination of the cause of death depends on access to medical care or when attribution is politicized or stigmatized. Such factors were likely important contributors to the significant underreporting of opioid-related overdose as a cause of death in the recent past, which had implications for the delayed response to the opioid crisis.[12] As the United States reckons with making much-needed investments in its public health system in response to the pandemic, it would be a mistake not to include improvements to the death investigation system in these conversations. AJPH

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All authors contributed equally to the drafting and editing of this article.

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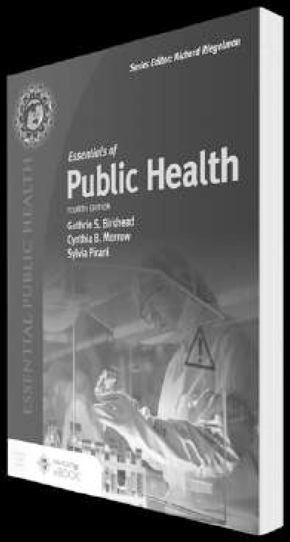

S54 Editorial Stokes et al.

Death Certification in the United States

Sally S. Aiken, MD

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Death investigation in the United States is governed by a mishmash of laws that define jurisdiction and roles using a mixture of medical examiners (MEs), coroners, justices of the peace, districts, sheriff-coroners, and prosecutor-coroners working in more or less centralized systems. Coroners are elected officials with jurisdictional authority for death certification. Typically, coroners are not physicians and have few requirements for training or qualifications. By contrast, MEs are appointed positions filled by physicians with legal authority for death investigation. Many MEs are board certified by the American Board of Pathology in Forensic Pathology and can perform autopsies. In the United States there are approximately 2300 death investigation jurisdictions.[1] The majority are coroner offices, with many located in smaller, more rural counties. About one half of the US population is served by an accredited ME office; these often have jurisdiction over large cities, counties, or whole states.

Widespread local and regional variation exists regarding the statutory authority to complete death certificates. The funeral home typically begins the process, inserting demographic information provided by family members or other knowledgeable sources.[2] Community physicians, other health professionals (e.g., nurse practitioners), coroners, or MEs provide cause and manner of death and other public health information.

The death certificate has dual purposes. It is primarily a public health document, revised periodically to meet public health needs to track population mortality. Over the years, it has been expanded to include data about tobacco use and maternal mortality. In Washington State in 2020, it was updated to add fields for COVID-19 testing results. For families, though, death certificates become part of family history. And death certificates also are used for "proof of death" certification for insurance companies, the Social Security Administration, and banks. Several states have begun to address its dual purposes by issuing "short-form" certificates that exclude cause and manner of death as well as sensitive information and "long-form" certificates with access restricted to public health agencies and immediate family members.

Death certificates can sometimes fuel family and community controversy. The listed manner of death may not comport with legal definitions. In most jurisdictions, traffic fatality deaths are classified as "accidents," although legally some are vehicular homicides. Family members may strongly object to a death classified as "suicide." Deaths during legal intervention are scrutinized by the public and law enforcement.

The National Association of Medical Examiners has partnered with the Centers for Disease Control and Prevention on several initiatives to improve the death certificate. One is to standardize the practice of listing specific drugs or medications on the certificate to track the opioid epidemic.[3] A second is to seek better certification of deaths during hurricanes and other natural disasters. This was instituted partly because of controversy over mortality statistics in Puerto Rico after Hurricane Maria.

But MEs and coroners, most experienced with certification, complete a minority of death certificates in the United States. Indeed, in my county the ME office certifies about 12% of all deaths in the county. The focus is on unnatural deaths: homicides, suicides, and accidents. These require investigation to ascertain correct certification. By contrast, community health care providers certify natural deaths, which are the majority of deaths. However, repeated surveys of community physicians reveal inadequate training in completing death certificates. Correspondingly, studies using death certificate data find inherent problems in accuracy.[4]

COVID-19 has renewed concerns about weaknesses of the death certificate process. For example, confusion about how COVID-19 comorbidities should be reported results in delay and accuracy concerns.[5] The fact that hospital physicians sign the great majority of COVID-19 death certificates underscores the need for better training of physicians in death certification as part of their medical school or residency education. AJPH

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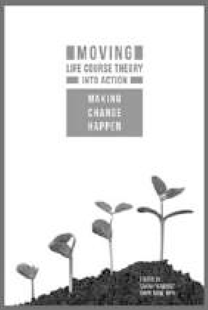

Seeing Death Up Close: Funeral Directors as Forgotten First Responders in the COVID-19 Pandemic

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I am a New York and New Jersey licensed funeral director, one of the underrecognized "first responders" in the COVID-19 pandemic. As funeral directors, we normally interface with both the public health world of documenting vital statistics and the families and friends of the deceased. In public health, the funeral director is one of three required signatories for the certified death certificate, the others being the medical provider and the registrar in the municipality where the death occurred. We complete vital statistical information on the death record, the precursor to the death certificate. We are also tasked with ensuring correct wording of the cause of death (COD). As mandated reporters, we alert the local medical examiner's office when the COD involves an injury, poisoning, or some manner other than "natural."[1]

In February 2020, as deaths began to rise in New York and New Jersey, the local medical examiners' offices were inundated because all suspected COVID-19 deaths were being reported to their office. Funeral directors, medical providers, and registrars were in the dark as to how to classify these deaths within the Electronic Death Registration System. Finally, in April 2020, the National Vital Statistics System provided guidance clearly stating that COVID-19 could not be reported as the immediate COD. Death certificates include three or four lines for COD. The immediate COD is the final disease or condition resulting in death; the remaining CODs are sequentially listed conditions with approximate interval to death onset.[2]

This guidance led funeral directors, overwhelmed themselves with the numbers of deaths, to have to request already exhausted medical providers to change COVID-19 deaths on the Electronic Death Registration System as the immediate COD to another cause to prevent having the death certificate rejected by the registrar. At the same time, exhausted doctors protested that they did not have time to change the COD. If they did take it off, they would substitute a more generic natural cause. Families who came to funeral homes were expressing their own understandable traumas being unable to be with their loved ones at the time of their death. The COVID-19 alterations in how services were to be held were disruptive and traumatizing as well. Hospital morgues were filled to capacity with people who died of a strange and terrifying virus. Refrigeration trucks were quickly filled as soon as they were parked outside hospitals.[3] Cemeteries could not keep up with the demand. Some even closed temporarily. Local crematories were overwhelmed, requiring bodies to be transported hundreds of miles to other crematories. Countries were shutting down borders and not allowing repatriation of bodies for burial.[4] All religious houses closed for funeral gatherings and cemeteries were not allowing gatherings of groups in excess of very small numbers. For funeral directors, who are committed to our sacred responsibilities to the dead, their families, and to public safety, these events were especially difficult.

Making things more difficult, we had no guidance early in the pandemic from the Centers for Disease Control and Prevention or any public health agency as to the transmission risk of COVID-19 from the deceased. Most traditional funeral rites were suspended, such as embalming and Jewish and Muslim preparation of the dead.[5] Thankfully, as officers of the Metropolitan Funeral Directors Association—the trade organization that serves our industry in New York City—I and my fellow officers were in constant contact with the New York City Office of Medical Examiners and with the New York State Funeral Directors Association. They were an enormous help in working with politicians to address the needs of funeral directors. Eventually the National Guard was sent in to help transport the dead to temporary holding areas until licensed funeral directors could attend to them. Other funeral directors from around the country were given temporary legal authority in New York and New Jersey to assist us.[6]

We also sought the wisdom of more weathered colleagues with experience in the AIDS epidemic to deal with social concerns and biohazard threats. The stigma of AIDS had led families to request changes in the COD for privacy reasons. But doctors were mandated at the time to report it. The contentiousness of this issue resulted in the New York City death certificate not listing any type of COD; it only states "natural causes." (New York City has its own death registration system apart from New York State.) We were seeing the same happening with COVID-19. Though a death certificate in New York City could list "natural causes," death certificates in New Jersey and New York State specified COVID-19 sequentially as a contributory cause. But families would sometimes request that COVID-19 not appear anywhere on the death certificate. Previous AIDS experiences also underscored the need for barrier precautions for funeral directors and their staff until transmission risk could be determined. Our trade associations helped procure supplies of personal protective equipment and face masks for those running dangerously low during those early months.

Starting April 12, 2021, the Federal Emergency Management Agency began offering COVID-19 funeral assistance—up to $9000 in compensation—to families for funeral services. Yet, many doctors, in their frustration with the National Vital Statistics System, did not list COVID-19 on the death certificate. Furthermore, those families who did not want COVID-19 listed on the death certificate might now wish otherwise. Funeral directors are fielding daily phone calls from families who want help amending the COD. Undoubtedly, we will never truly know the real COVID-19 death toll of 2020. So many people died scared and alone in hospitals that were desperately overburdened. So many families were torn apart by such sudden, unexpected deaths. We funeral directors were and still are the last loving human touch for these people. Like other first responders, we carry deeply the traumas of this pandemic. AJPH

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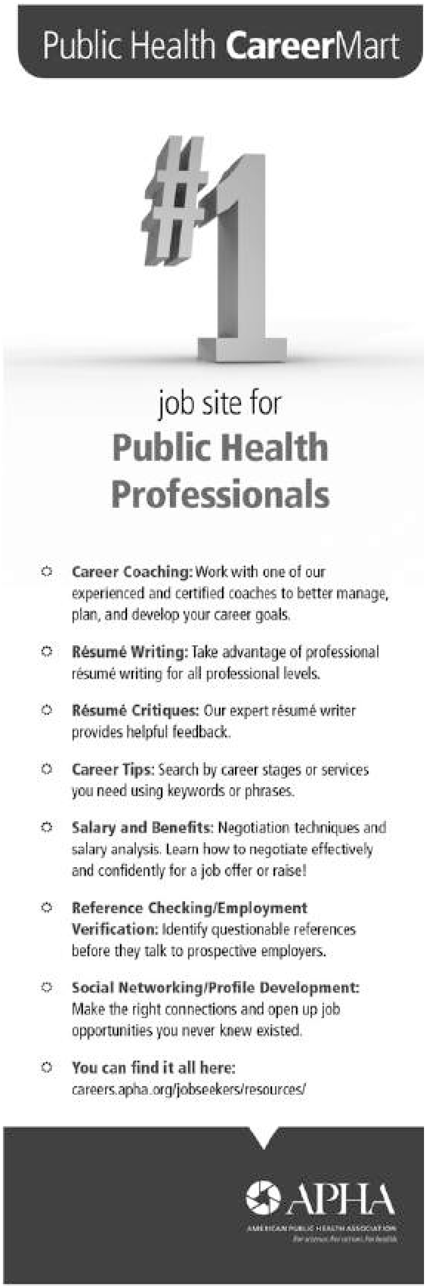

Estimating COVID-19–Related Mortality in India: An Epidemiological Challenge With Insufficient Data

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As of May 16, 2021, India, a country with a population of 1.38 billion, was second only to the United States in the total number of reported severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) cases (nearly 25 million) and third following the United States and Brazil in total reported deaths (> 270 000).[1] Data from seroprevalence studies and limited excess mortality calculations offer evidence that the actual numbers of infections and deaths are likely much larger than the ones reported.[2,3]

We recognize that multiple challenges lead to underreporting of COVID-19 fatalities including (1) deaths that occur outside of hospitals that either are not captured or incur a lag, (2) deaths that are classified under comorbid illnesses, (3) deaths that are attributable to low access to quality health care or a shortage of health care resources, and (4) deaths that are undetected as a result of an inadequate COVID-19 testing program. Our review of the existing evidence suggests that the problem is particularly acute for India, where a large number of deaths (especially ones happening outside a health care facility or in rural areas) routinely remain medically unreported.[4]

CURRENT ESTIMATES

We report these numbers as of May 16, 2021. The overall case fatality rate (CFR) in India has remained low (1.09%) relative to estimates from other countries (1.77% in the United States, 2.78% in Brazil, 2.07% globally).[1] However, India has a young population (e.g., proportion of the population aged ≥ 65 years is 6.4% in India vs 9.3% in Brazil and 16.5% in the United States) and, as such, age-specific mortality comparisons are more meaningful. The first and second waves of the pandemic in India are characteristically different in terms of both infections and deaths. The CFR for wave 1 is 1.4%, and the CFR for wave 2 is currently 0.8%. Some state-specific numerical estimates are presented in Table 1. It is hypothesized that the reduced CFR in wave 2 is attributable to underreporting, pending data reconciliation from diverse sources, and a large number of infections in younger age groups with a lower risk for severe clinical presentation of SARS-CoV-2, an assertion yet to be verified.[5]

UNDERREPORTING OF INFECTIONS AND DEATHS

To estimate infection fatality rates (IFRs), we, among other researchers, have used epidemiological models and seroprevalence surveys.[6] Such models[7] indicate that the underreporting factor is around 10 to 20 for cases and around 2 to 5 for deaths, based on data from wave 1 in India. According to these studies, the IFR for India is roughly 0.1% using observed death counts and 0.4% after incorporating underreporting of deaths (Table 2). The former resembles early estimates for Mumbai, Srinagar, and Karnataka using observed fatalities (0.09%, 0.06%, and 0.05%, respectively).[11,12]

We note that anecdotal and media reports corroborate model estimates. For example, during wave 1, a group of volunteers collected reported deaths from obituaries in newspapers and found the death count to be almost twice that officially reported.[13] Likewise, during this recent surge, a *New York Times* article noted that authorities in Gujarat reported between 73 and 121 daily COVID-19–related deaths in mid-April, contradicting a leading newspaper in Gujarat that cited the number as several times higher (around 610 daily deaths).[10] Recently, an excess death

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TABLE 1— State-Level Comparison of COVID-19 Attributed Mortality for the First and Second Waves in India: March 24, 2020–February 14, 2021, and February 15, 2021–May 15, 2021

State	Wave 1: Mar 24, 2020–Feb 14, 2021[a]		Wave 2: Feb 15, 2021–May 15, 2021[a]	
	No. of Cases Reported	No. of Deaths Reported (CFR)[b]	No. of Cases Reported	No. of Deaths Reported (CFR)[b]
India	10 915 905	155 169 (1.42)	13 766 623	114 550 (0.83)
Maharashtra	2 064 181	51 526 (2.50)	3 279 785	28 983 (0.88)
Punjab	176 275	5 696 (3.23)	314 457	5 996 (1.91)
Gujarat	265 213	4 399 (1.66)	479 165	4 638 (0.97)
Karnataka	945 237	12 271 (1.30)	1 226 661	9 169 (0.75)
Kerala	1 004 041	3 986 (0.40)	1 114 128	2 354 (0.21)
Delhi	636 916	10 890 (1.71)	750 465	10 353 (1.38)

Note. CFR = case fatality rate.
Source. COVID19INDIA (https://bit.ly/3waJWzc).
[a] Wave 1 is defined as starting from March 24, 2020, when the first nationwide lockdown was implemented in India. Wave 2 is defined as starting from February 15, 2021, when the national effective reproduction number for COVID-19 in India crossed unity. Estimates for wave 2 are computed through May 15, 2021, which is the latest available data at the time of this report.
[b] CFR is the number of reported deaths divided by the number of reported infected cases.

calculation based on comparing death certificates issued in the state of Gujarat[14] showed that while the state reported 4218 COVID-19–related deaths during March 1 to May 10, 2021, an estimated 61 000 excess deaths remained uncounted, indicating an underreporting factor of nearly 15. Moreover, comparisons to past years of satellite images revealing fires emitting from burial pyres has imprinted the sheer scale of additional lives lost to the pandemic in April 2021.

UNIQUE FEATURES

As a result of delayed detection, the proportion of COVID-19–related deaths within a narrow time-to-death window (from the date of confirmed diagnosis) was higher in select regions compared with the global findings. For example, a study found a considerable 18% of deaths across the states of Tamil Nadu and Andhra Pradesh occurred within 24 hours of diagnosis,[9] suggesting a substantial lag in the initial diagnosis of COVID-19 compared with other countries. In wave 2, a strained health system, a deficit of intensive care unit beds, and inadequate oxygen monitoring for at-home isolation have collectively exacerbated this issue. The CFRs in India vary considerably across states (e.g., among large states, Kerala has the lowest and Punjab has the highest CFRs). This geographical heterogeneity is also reflected in the (albeit limited) regional excess death calculations available for 2020.[15]

DATA PAUCITY

India, unlike other countries, does not have robust and readily available mortality data that can be used for analysis.[16] The Ministry of Health and Family Welfare shared age- and sex-disaggregated COVID-19–related data at the start of the pandemic, but the official reporting of this information quickly stopped. We only have access to sporadic release of charts and tables in briefings and media reports. We join the research community in calling for these data as well as information on comorbidities, which are necessary to track age- and sex-specific trends, to identify high-risk subpopulations, and to validate hypotheses regarding rates of infections, severe cases, and deaths within subgroups of interest.

In terms of longevity and cause of death, India's most recent reporting of life expectancy and all-cause mortality estimates are from 2014 to 2018 and 2010 to 2013, respectively, precluding any meaningful, timely study of all-cause or excess mortality. According to the latest global excess mortality study (January 2021), 77 countries report data on all-cause mortality, enabling experts to compute country-specific excess mortality, which is largely considered the gold standard for estimating the burden of COVID-19.[16] India is a notable exception[16]; in our opinion, the release of these figures is sorely needed.

IMPACT OF INSUFFICIENT DATA

Deficiency in the COVID-19 death reporting has harmful ramifications. It limits modelers' ability to predict the course of the pandemic, gauge its impact, and estimate health care resource needs—including oxygen supplies and hospital beds. Without disaggregated epidemiological data, linked with genomic sequencing, assessing the lethality of virus strains and evaluating vaccine effectiveness becomes nearly impossible. This data-deficient environment stunts overall policy efforts to improve public health outcomes and

TABLE 2— State-Level Summary of the Latest Issued COVID-19 Attributed Mortality in India During 2020–2021

	As of May 16, 2021[b]		As of Jan 31, 2021[c,d]		
State[a]	No. of Cases Reported	No. of Deaths Reported (CFR)[j]	IFR	Adjusted IFR	Excess Deaths[e–i]
India	24 965 079	274 417 (1.09)	0.13	0.46	NA
Maharashtra	5 378 452	81 486 (1.51)	0.46	0.97	NA—Mumbai: ~ 21 000
Punjab	497 705	11 895 (2.38)	0.36	1.01	NA
Gujarat	752 619	9 121 (1.21)	0.28	0.59	~ 61 000
Karnataka	2 203 462	21 837 (0.99)	0.17	0.43	NA—Bengaluru: 10 248
Kerala	2 147 968	6 429 (0.29)	0.06	0.14	~ –16 000
Delhi	1 393 867	21 506 (1.54)	0.06	0.38	NA—New Delhi: ~ –5 800

Note. CFR = case fatality rate; IFR = infection fatality rate; NA = not available.

[a] The states that have issued excess deaths calculations as of May 16, 2021 (and Punjab) are included in this table.

[b] COVID19INDIA (https://bit.ly/3waJWzc).

[c] Purkayashtha et al.[8]

[d] IFR and adjusted IFR are estimates from an extended susceptible–exposed–infected–removed (SEIR) model, where adjusted IFR accounts for underreporting of COVID-19 deaths.

[e] Annual excess deaths for the city of Mumbai and the state of Kerala are both for 2020.[9]

[f] Excess deaths for the state of Gujarat are from March 1 to May 10, 2021.[10]

[g] Excess deaths for the city of Bengaluru are from January to July 2020 (https://bit.ly/351BV3V).

[h] Excess deaths for the city of New Delhi are from April to June 2020 (https://bit.ly/3gqcSNj).

[i] Excess deaths calculations vary across regions, as approaches depend on underlying assumptions regarding the number of expected deaths. The general framework includes obtaining the difference between the observed death count and the average expected death count, as derived from previous years.

[j] CFR is the number of reported deaths divided by the number of reported infected cases.

health care infrastructure for the future. For example, without knowing who are dying and the magnitude of COVID-19–related fatalities, one cannot design social and economic policies to protect the vulnerable and support the families left behind.

RECOMMENDATIONS MOVING FORWARD

We offer general recommendations herein for systematizing the collection and advancing the quality of all-cause and disease-specific mortality data in India. The Indian government recently announced a pilot trial of a personal digital health identifier, which would ultimately serve as an electronic key to a health data repository for each individual nationwide.[17] Integrating data across health systems offers a solution to capturing all-cause mortality in a more nationally representative way. With successful implementation, and multiplatform linkages, a digital health identifier would enable comprehensive analysis of health care outcomes via continuous reporting and a breadth of available individual-level data.

Heterogenous data linkage holds promise for approximating unreported deaths, such as through tracking inactive Aadhaar cards (akin to Social Security cards in the United States), bank accounts, phone numbers, and social media accounts. Inspection of life insurance claims may also complement indirect validation efforts in urban areas. Innovative strategies for surveillance using community health care and Accredited Social Health Activist workers are needed in rural India, where a proper reporting system is largely absent. We recommend strengthening the Civil Registration System by leveraging community engagement and partnerships as well as collaborating with community and religious leaders to encourage prompt reporting by family members of the deceased. We need continued attention to medical certification of deaths and mandatory linking to the Civil Registration System for India to meet international standards. Death not being reported reflects dishonor to the entire life of a person. When not captured and analyzed in a timely manner, the existing health inequities are further exacerbated. A fortified nationwide vital surveillance system, as well as timely and comprehensive data reporting and cogent analysis, is at the heart of fighting this pandemic. An investment in a robust data ecosystem now will help safeguard India against future health crises. AJPH

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All authors contributed to the research, writing, editing, and review of this commentary. M. Salvatore and L. V. Zimmermann performed the numerical analysis. B. Mukherjee guided overall execution.

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Tracking Incarcerated Individual Mortality in Local Jails

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Mortality trends in most of America's 3000 local jails are almost impossible to discern because jail-by-jail death data collected by the federal government over the past 20 years is kept secret—unavailable to the public, news organizations and researchers, and even government officials.

Based on an obscure statutory restriction, jail mortality data released by the US Bureau of Justice Statistics is aggregated to the state and national level.[1,2] As a result, it is impossible in most jurisdictions to answer key health and safety questions about specific jails: How many incarcerated individuals are dying and how? Do different health care models affect jail mortality? Are certain categories of incarcerated individuals dying in outsized numbers? The answers can reveal a lot about the conduct of local jails, which typically are managed by county sheriffs or local police departments, and the effectiveness of local and state oversight.

Reuters filled the information gap by requesting 12 years of death data from 523 local jails or jails systems—every jail in the country with an average of 750 or more incarcerated individuals, plus the 10 largest locally operated jails in each state, regardless of size.[3–5] Our "Dying Inside" project, which required more than 1500 public records requests, documents 7571 deaths of incarcerated individuals from 2008 to 2019 in those facilities, which hold more than half the total US jail population.

The data, which provides the largest-ever public accounting of US jail deaths, reveals how dozens of jails routinely post death rates two or three times the national average. Two thirds of the deaths we identified involved individuals awaiting trial, unconvicted and presumed innocent. Thousands perished from preventable causes, including at least 2070 from suicide and at least 618 from drug and alcohol poisoning. In recent years, incarcerated individuals died at higher rates in jails that privatized their medical services by hiring one of a handful of leading correctional health care companies. And a growing number of the incarcerated individuals who died were women, often held in male-oriented facilities ill-equipped to handle their needs.[3–7]

It took five Reuters reporters nearly two years to collect the records; we ultimately got responses from nearly 100% of the jails we surveyed. Although some jails refused to provide all the requested material, we strove to capture as much information as possible about each deceased inmate, from age, gender, and race and ethnicity, to cause of death and length of incarceration. We also collected each jail's annual population and data on how it managed medical and mental health care (i.e., whether those services were privatized through a correctional health care company or managed by a government entity, such as a sheriff's department or local public health agency).

We analyzed the data using statistical models developed with help from several outside experts. For example, in comparing death rates at jails with privatized health care versus jails where medical services are managed by local governments, we developed a statistical model to control for some factors that might affect jail mortality, including county mortality rates and jail size.

Our project has been a case study in the value of jail-specific mortality data. In West Virginia and Mississippi, Reuters' data spurred legislators and judicial reform groups to demand death investigations and propose bills to set standards for jail operations and accountability.[8,9] In Georgia, lawmakers held a hearing on jail conditions and promised legislation this year to boost oversight.[10] Local news outlets across the country leveraged Reuters' data for stories identifying jails with troubling mortality trends. And members of Congress vowed to bolster collection of inmate mortality data and find ways to make it public so jails with extraordinary death rates can be held accountable.[11] AJPH

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Machine Learning Can Unlock Insights Into Mortality

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The study of mortality is fundamental in public health research, but our ability to derive detailed insights is often limited by the practical constraints of the available data. Although the National Vital Statistics System maintains a national record of death certificate data enabling basic research on mortality trends and life expectancy, clinical information on the context of a given death in national death records is limited. When the necessary information is available, the ability to examine clinical details surrounding death and health indicators in the period before death enables research that can meaningfully inform public health strategies and interventions.

Insurance claims data can fill gaps in mortality research by providing details about diagnosed health conditions and key health care services a person receives before death, such as surgical procedures, laboratory tests, and drug prescriptions. This level of granularity composed of data that are continuously and prospectively collected for each patient offers insights that are not available with vital statistics alone and opens the door to uncovering how medications, health conditions, and health encounters may be associated with mortality.

A major limitation in mortality research is that data sets that have rich longitudinal health information (claims) and those that have recorded death dates (vital statistics) are often separate, and linkage may be prohibitively expensive or prohibited because of data privacy restrictions. We discuss the research implications of having disparate streams of health and mortality data; introduce how machine learning can help overcome these limitations; highlight important considerations for machine learning, including the risk of algorithmic bias; and briefly discuss best practices for applying machine learning to enhance public health research.

RESEARCH IMPLICATIONS

Studies using detailed longitudinal health data to better understand risks of mortality are limited to subpopulations whose claims data can be linked to death records (e.g., from Medicare claims); consequently, these studies present limited generalizability (e.g., to commercially insured populations). In some instances, inpatient claims data might contain discharge status reflecting death in the hospital. However, the Centers for Disease Control and Prevention estimates that the majority of all deaths occur outside the hospital (72% in 2019), and therefore deaths that occur in a hospital are just a small part of total mortality.[1] Other than data on cases for which hospital discharge status may indicate deaths that occur in a hospital, claims data do not regularly include death events. Individuals who die show a “disenrolled” status in their enrollment record, and researchers are largely unable to separate those who died from those who ended coverage with the insurance plan or employer.

Incomplete death data and the inability to differentiate between disenrollment because of death and disenrollment because of changes in insurance coverage present a significant missing data problem in health outcomes research. In epidemiologic terms, death is a competing risk. Incorrectly assuming that disenrollment is uninformative (i.e., independent of clinical disposition) and failing to account for death as a competing risk (when risk of death is nonnegligible) will induce bias in risk estimates for primary outcomes. Berry et al. demonstrate this bias empirically in a study of second hip fracture among elderly patients, showing that incidence of second hip fracture was 21% when not accounting for death as a competing risk and 12% when properly incorporating death information.[2] More recently, a study examining patients hospitalized for severe COVID-19 estimated the percentage of patients with clinical improvement after treatment with remdesivir.[3] By failing to account for the 13% of patients who died after receiving remdesivir, the authors overestimated the percentage of patients with clinical improvement by 10 percentage points.

MACHINE LEARNING AS A SOLUTION

Although custom linkage between claims and death data is challenging because of privacy concerns, innovations in privacy-preserving methods such as differential privacy may improve data availability and usability. When differential privacy allows claims-based linkage between clinical data elements and death status, machine learning can be trained in these linked data. For instance, vendors of administrative claims databases often have internal access to death data that can be analyzed to create algorithms differentiating disenrollment because of death and disenrollment because of changes in insurance coverage in claims-based studies. Effectively, this translates to distinguishing death from what may be considered uninformative administrative censoring.

In contrast to traditional statistical methods, which are better suited to testing prespecified hypotheses, machine learning focuses on empirical prediction of an outcome, irrespective of the model's parametric form (i.e., explanatory power).[4,5] Machine-learning methods can efficiently analyze thousands of potential predictors using data-adaptive identification of complex patterns, including nonlinear relationships and high-order interactions, optimizing predictor selection for a final algorithm.[6] By optimizing predictive performance, a machine-learning algorithm of mortality in claims data can be used to effectively impute missing or incomplete death status.

Reps et al. illustrated the potential for this type of work using an administrative claims database that had death records up to 2013 (sourced from the Death Master File) to develop and test a machine-learning algorithm for death status at the end of observation.[7] In the spirit of this work, new predictive algorithms based on machine learning can be developed in different data sources or those with more recent death data. Such algorithms can be disseminated for use in claims-based studies to address mortality as a primary outcome or competing risk, dramatically mitigating potential bias and broadening the scope and utility of health outcomes research.

POTENTIAL PITFALLS OF MACHINE LEARNING

Although machine-learning methods have the potential to enable research dealing with mortality, these methods have limitations to be considered. Predictive algorithms developed through machine learning may be subject to less human bias (e.g., model misspecification) given the data-driven nature of these methods; however, the data themselves can be inherently biased. If the input data used to train algorithms lack diversity or reflect structural biases, output models will not generalize across populations. Use of these algorithms can result in algorithmic bias, perpetuating existing inequities.[8] Obermeyer et al. show that for a given level of health, structural inequalities in access to care in the United States result in lower health care costs generated by Black patients than by White patients.[9] Subsequently, the use of an algorithm to identify patients who are most likely to benefit from additional resources based on predicted health care costs exacerbates systemic racial biases by preferentially identifying White patients to be more likely to benefit from additional resources.

For death specifically, racial disparities in the accuracy of death records (race and cause of death) can cause disparities in algorithm performance in certain subgroups. Previous work has found that race was more often misclassified on National Death Index records for American Indians and Alaska Natives,[10] and research conducted by the National Center for Health Statistics found that linkage rates of participants of Hispanic or Asian/Pacific Islander descent with National Death Index records were considerably lower than were those of non-Hispanic White patients.[11] These findings imply that what is often considered the "gold standard" for death recording has differential accuracy across race. Another study comparing race as recorded on death certificates to race reported by next of kin found that cause of death affected race reporting on death records, suggesting that racial information in vital statistics may be influenced by racial stereotypes.[12] This is particularly problematic for algorithms aiming to predict cause of death.

CONCLUSIONS

Death is a critical outcome for many research questions and a significant competing risk for many others. Machine learning can be used in large claims data to unlock insights into mortality, facilitating new public health research. With the growing availability of electronic health data, along with the gaining momentum of machine learning, large claims data are a frontier for mainstream public health research. These data-driven methods are flexible and, in the case of defining death in insurance claims data, can help examine data points from millions of patients, evaluate many predictors, identify the most important factors associated with death, while evaluating complex interactions at a scale not previously possible. In addition to predicting death in claims data, machine-learning methods have been applied to vital statistics data sets themselves, making mortality data more representative of minority populations[13] and providing more granular time estimates of often misclassified deaths such as suicide.[14]

Researchers must be aware that machine-learning tools are not impervious to human bias. If there are biases in whose experience is recorded, machine-learning tools can entrench existing race-based health disparities.[8,9] In an evaluation of approaches to reduce bias in machine-learning models, Park et al. illustrated several methods for evaluating algorithmic bias and found that a reweighting method was most successful in reducing bias.[15] When using machine learning, the population represented by the input data for algorithm creation must be considered, with an understanding that algorithms may not generalize to other populations. An algorithm developed in one population cannot necessarily be applied to a different population. External validation in appropriate populations is an important component of any machine-learning algorithm. Additional important aspects include a deep understanding of the data and potential biases in the underlying mechanisms of data generation, evaluation of algorithm performance across diverse subgroups, and transparency in the dissemination of algorithmic inputs, parameters, and outputs.[8]

When implemented rigorously using these best analytic practices, machine-learning algorithms can also address existing biases in health care. In a recent study examining racial disparities in pain, Pierson et al. found that compared with standard radiologic measures of pain severity that were developed in White patients, a newer machine-learning algorithm trained on racially and socioeconomically diverse data better captured pain in underserved populations.[16] Machine learning is a powerful tool for analyzing large amounts of data for clinical prediction. When applied to claims data linked to vital statistics, machine learning presents an opportunity to create algorithms to predict death, thus unlocking new possibilities into mortality research and reducing bias in estimates of other health outcomes of interest. AJPH

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J. C. Young led the structuring of the article and authored the introduction, potential pitfalls, and conclusions sections and portions of the machine learning and research implications sections and was responsible for soliciting feedback and integrating the text and author contributions. C. Pack led the authoring of the machine-learning methods text. C. Pack, T. B. Gibson, F. Yoon, D. E. Irwin, S. Shiv, T. Cooper, and N. Dasgupta reviewed multiple versions of the text and provided comments. T. B. Gibson led the authoring of the implications on research text. F. Yoon was heavily involved in machine-learning efforts and assisted with the text describing these methods. D. E. Irwin provided general project direction and contributed expertise on claims data and mortality. S. Shiv provided oversight for the study team, was involved in discussing methods and clarifying the text, and reviewed the text before submission. T. Cooper managed the larger project and coordinated the study team. N. Dasgupta was responsible for the synthesis of the original project and team, detailed the direction for the article and the vision for the overall message, made substantial additions to the article, and provided feedback.

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Monitoring Deaths in Police Custody: Public Health Can and Must Do Better

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Police accountability and transparency have been key demands of the Black Lives Matter protests that first took to the streets in 2014 and continued in 2020. However, six years after a police officer killed Michael Brown in Ferguson, Missouri, the United States does not even have an official nationwide system that documents all deaths in police custody, much less one that provides detailed and timely data to the public. This lack of transparency can, in part, be seen as a failure of public health infrastructure.[1] Mortality surveillance is a key function of public health, one that entails enumerating deaths, describing the circumstances under which deaths occur, and using these data to inform systemic changes that can prevent future harm. The American Public Health Association adopted an official policy statement in 2018 that, among other recommendations, called on public health agencies to collect better data on police killings.[2] We build on this call to action by describing the processes that lead to undercounting of deaths in custody in national mortality data and the paucity of critical details about circumstances that led to those deaths. We outline three suggestions that would improve data collection on deaths in custody and strengthen efforts toward police accountability.

CURRENT STATE OF MONITORING DEATHS IN POLICE CUSTODY

Under federal law, the Deaths in Custody Reporting Act (DCRA) defines a "death in custody" as the death of a civilian who was being detained, pursued for arrest, or transported by law enforcement. (The definition also includes death during incarceration, which is beyond the scope of this editorial.) Whereas the term "legal intervention" connotes that use of physical force by an officer caused the death, "death in custody" is a broader category that includes legal intervention as well as deaths whose link to use of force is unclear or contested (e.g., deaths following the use of a Taser, whose link to mortality is often disputed) and deaths that occurred in the absence of use of force (e.g., the decedent was struck by a car while pursued by law enforcement).[3,4]

The two national public health data sets that record certain US deaths in police custody are the National Vital Statistics System (NVSS) and the National Violent Deaths Reporting System (NVDRS), which we describe in detail. Beyond the realm of public health, several other national efforts aim to collect data on deaths in custody. The US Department of Justice (DOJ) administers two systems—the Arrest-Related Deaths Program (enabled by the DCRA) and the Supplementary Homicide Report—that rely on voluntary reporting; when assessed by the DOJ, both systems counted fewer than half of deaths in custody.[5] Various nongovernmental organizations also collect data on deaths in custody by compiling news media reports, an approach that has been previously assessed to capture more than 90% of police killings,[6] although their ability to capture other deaths in custody (i.e., deaths without a clear link to use of force) has not been assessed. Ongoing nongovernmental efforts include, among others, the *Washington Post*'s Police Shootings Database,[7] which only records fatal shootings, and Fatal Encounters, which reports a broader set of deaths in custody, including those that did not involve use of force. Finally, in 2016, the DOJ redesigned its Arrest-Related Deaths Program to incorporate news media sources along with voluntary law enforcement reporting.[8] However, it appears that the new program never went into effect during President Trump's administration.[9]

INVESTIGATING DEATHS IN POLICE CUSTODY

Public health documentation of deaths in police custody begins with a death investigation by a coroner or medical examiner (CME). A coroner is an elected county-level official who typically has little medical training, whereas a medical examiner is a physician who is appointed rather than elected. CMEs conduct or oversee autopsies, write narrative reports about the circumstances that led to death, and fill out the cause-of-death section on death certificates. These documents serve as the raw data that are later processed in state and national vital statistics systems.

Several issues with CME practices lead to poor data quality regarding deaths in police custody. The net effect of these practices is that deaths are undercounted and causal links between use of force and death are obscured. First, when filling out death certificates for individuals killed by police, CMEs often fail to indicate police involvement, even when they correctly describe police involvement in separate narrative reports.[10] This practice leads to undercounting in death certificate–based vital statistics systems. Second, a more complex set of issues arises for nonfirearm deaths in custody, such as death after Taser shocks, chokeholds, prone restraint (i.e., holding a civilian face down on the ground), or chemical restraint (e.g., forcible injection with ketamine at the direction of police). Autopsies after such deaths in custody often yield inconclusive results, and the CME must base determinations on other evidence, which may consist solely of officer testimony. In such instances, the medical cause of death is often unclear, and the manner of death (particularly, whether the death was an accident versus homicide) may be contested.[11] These nonfirearm deaths in police custody are rarely reported as homicides, even when they follow use of force, and the manner of death is often classified as accidental or undetermined.[6,12] Reporting practices regarding the manner and cause of death are often idiosyncratic and can be influenced by pressure that police and other government officials exert on death investigators.[13,14] Additionally, much of the forensics research that informs CME determinations regarding so-called "sudden deaths in police custody" involves conflict of interest, such as funding from Axon (formerly called Taser International) and funding from city governments in the context of wrongful death lawsuits against police.[15] Much of this research has involved attributing deaths in custody to a contested medical condition called "excited delirium" rather than alternative explanations, such as positional asphyxia, for which police would be held responsible.[16]

THE NATIONAL VITAL STATISTICS SYSTEM

The NVSS is maintained by the Centers for Disease Control and Prevention (CDC) through a compact with state governments and contains data on virtually all deaths in the United States. Police killings have been identifiable in the NVSS since it adopted the sixth revision of the *International Classification of Diseases (ICD)* in 1949. The *ICD* codes for police killings fall under the category of "legal intervention," defined as: "Injuries inflicted by the police or other law-enforcing agents, including military on duty, in the course of arresting or attempting to arrest lawbreakers, suppressing disturbances, maintaining order, and other legal action" (*ICD*, 10th edition, Geneva, Switzerland, 2010). Other deaths in custody (i.e., those for which the CME does not determine that use of force caused the death) are not considered legal intervention and are therefore not identifiable in the NVSS. The system's nationwide data collection over a long historical period allows for comparisons of legal intervention mortality rates between locations and over time. However, ascertainment for legal intervention in the NVSS is poor: one study found that nationally, 55% of deaths that met the criteria for legal intervention were misclassified in 2015 and instead were typically reported as assault-related injuries (i.e., the same category used for homicides perpetrated by civilians).[6] Whereas some states correctly reported more than 75% of legal intervention deaths, other states reported 0%.[6] As described previously, underreporting is largely the result of CMEs failing to indicate police involvement on the death certificate, particularly in the text field labeled "Describe how injury occurred." The National Center for Health Statistics uses the text fields to assign an *ICD* code and cannot assign legal intervention if sufficient data do not exist. NVSS misclassification rates are particularly high for legal intervention that does not involve a gunshot wound.[6]

The NVSS has several shortcomings in addition to under-ascertainment of legal intervention. One is the lack of detailed data on the circumstances of the death—beyond reporting the mechanism of death (specific *ICD* codes describe whether the legal intervention injury was inflicted by a firearm, blunt object, and certain other subcategories), there are no other details about the events that led to the death. Additionally, there is a long lag between a death and the availability of that death in NVSS mortality data—the data for a given year are typically only available toward the end of the next calendar year.

THE NATIONAL VIOLENT DEATH REPORTING SYSTEM

The NVDRS is a state-level surveillance system designed to collect details of circumstances under which violent deaths occur. Started in 2002, it gradually expanded to include all 50 states in late 2018. The NVDRS draws on a broad set of data sources, including death certificates, medical examiner reports, and law enforcement records, and it includes a wide array of variables such as precise location of an incident, types of weapons used, and the nature of the "victim-suspect" relationship.[17] Previous research suggests that underreporting of police killings is much lower in the NVDRS compared with the NVSS,[18] but to our knowledge, there have been no efforts to formally quantify NVDRS underreporting by comparing its counts to those in more comprehensive news media–based data sets. Moreover, the NVDRS—by design—excludes nonfirearm deaths that are ruled accidental,[17] which means that many deaths in custody with nonfirearm injury mechanisms are not captured. Finally, there is a long lag for data availability. The first year in which NVDRS data included all 50 states was in 2019, and the CDC anticipates that these data will not be available to researchers until late 2021.

RECOMMENDATIONS

We offer the following three recommendations to improve data collection on deaths in custody and strengthen efforts toward police accountability:

1. improve data collection and reporting practices,
2. establish mortality review committees for deaths in custody, and
3. reform death investigations.

Improve Data Collection and Reporting

The COVID-19 pandemic has shown that the CDC, state health departments, and local health departments can create online dashboards that provide the public with timely, disaggregated data on mortality. To our knowledge, the only analogous dashboards for deaths in custody are maintained, not by health departments, but by the state attorney general of California.[19] (Texas also maintained a similar website, but it was inconsistently available in 2020.) The California deaths-in-custody website provides individual-level data that include the responsible agency along with decedents' demographics and cause and manner of death. Public health agencies at all levels can follow this reporting model. Additionally, state health departments can explore adding legal intervention to the state list of notifiable conditions in jurisdictions where those lists are permitted by law to include injuries, which may improve timeliness of reporting.[1] Finally, the CDC should promote a "death in custody" checkbox on the standard US death certificate (the model on which each state bases its own death certificate), which is also a recommendation of the National Association of Medical Examiners,[20] to allow for easier identification of these deaths in vital statistics mortality data. NVDRS data collection procedures can be revised to include records flagged as deaths in custody.

Review Committees for Deaths in Custody

Health departments across the United States currently use "mortality review committees" to assess preventable deaths with complex social and medical causes. Although maternal mortality review committees are the most prevalent and have the longest history,[21] the model has also been extended to address infant and child mortality and fatal drug overdose.[22,23] These committees meet regularly and include death investigators, forensic pathologists, clinicians of various specialties, public health officials, and members of relevant community organizations. The committee process entails reviewing all available information on the context of a death and then reaching agreement about the medical and social causes that led to the death. Committees release reports that address common, recurring themes from their mortality reviews along with recommendations to prevent further deaths. In New York City, for example, the Maternal Mortality Review Committee releases reports to the New York City Council. In some cases, the review process may also lead a participating death investigator to change the cause or manner of death determination. The review committee model should be extended to include deaths in police custody. These committees can explore not only the role of police practices that can lead to death, but also the systemic shortcomings of social services, mental health treatment, and societal responses to drug use that are often involved in deaths in custody.

Reform Death Investigations

CMEs have close working relationships with police, on whom they rely for access to crime scenes and evidence when investigating homicides, suicides, and drug overdoses. This relationship between police and death investigators can give rise to conflicts of interest in typical cases and even more so in particular California counties, where the sheriff-coroner position is combined into a single role. The National Association of Medical Examiners has called for medical examiners from an outside jurisdiction to investigate deaths in police custody.[19] Additionally, California, in particular, should continue its process of separating death investigations from sheriff's office investigations. Death investigator independence is essential to determining whether police use of force contributed to a death in custody. Finally, the National Institutes of Health, the CDC, and other federal agencies should proactively fund additional forensics research on the physiological causes of deaths in custody as an alternative to research funded by interested parties such as Axon. This research can help to inform and improve cause and manner of death determinations.

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The authors have no conflicts of interest to disclose.

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Mental Health and Mortality in a Time of COVID-19

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There is no question that mental illness contributes to an enormous burden of disability worldwide. Unipolar depression, for example, is the leading cause of disability as measured by years lived with disability.[1] Substance use disorders are also a leading cause of disability in several countries worldwide. It is also widely understood that mental health in populations has worsened during the COVID-19 pandemic, with several population-based studies now showing a two- to three-fold increase in mood-anxiety disorders.[2]

Despite the ubiquity of mental illness, its contribution to overall burden of disease, and increase in prevalence during recent years, we seldom consider mental health and its association with mortality. We think this is a substantial oversight and one that is worth addressing through a recalibration of the academic and public conversations on mortality. There are three reasons why mental health matters to mortality in general but perhaps particularly so in a time of COVID-19.

First, there is a direct causal link between some forms of poor mental health and mortality. Principally, for mood-anxiety disorders, it manifests as self-inflicted harm and death by suicide. We know, for example, that persons who have severe depression are 2.2 times more likely to die by suicide than persons with mild depression.[3] Suicide, in turn, is one of the leading causes of death for younger persons throughout the world.[1] In the context of the COVID-19 pandemic, data are still unclear as to whether the increasing prevalence of mental illness will also be associated with an increase in suicide, although one early report has found a substantial increase in emergency department presentations for both self-harm and mental health conditions throughout the United States.[4] With record unemployment levels, it is not implausible that suicide may increase during the pandemic because of exposure to stressors such as job loss.[5] Substance use disorders are also linked with mortality, particularly through unintentional drug overdoses. The aforementioned emergency department visit study also reported an increase in visits for opioid overdoses during the COVID-19 pandemic.[4] The United States was already in the midst of an opioid epidemic when the pandemic struck, and all evidence points to an increase in overdose mortality in 2020, exacerbating trends in mortality that were just beginning to abate before the COVID-19 pandemic hit. It is likely that greater confinement to home and absence of opportunities for other engagements contributed to this increase in mortality, illustrating the link between behavioral disorders and mortality during times of social and economic upheaval.

Second, there is a clear link between a range of more severe mental illness and mortality. For example, we know that persons with psychotic disorders have three-fold higher mortality rates than persons without these disorders and a commensurately shorter life expectancy.[6] This is also true for persons with other severe mental illness and is likely the result of a combination of more limited access to health care and a greater burden of risk behaviors that contribute to poor health. It remains to be seen whether the lack of access to routine health care experienced during the COVID-19 pandemic will also contribute to greater mortality among persons with severe mental illness.

Third, core to our understanding of mental health and mortality is that persons with mental illness die predominantly of the same conditions as people of all populations, principally noncommunicable disease (NCD). However, a greater burden of these NCDs fall on persons with poor mental health who have both earlier onset and greater severity of NCD. This association is likely caused by greater prevalence of risk behaviors, such as smoking, use of illicit substances, and obesity, and potentially by specific biologic mechanisms that characterize the co-occurrence of mental health and physical health.[7] Higher socioeconomic position is associated with both improved NCD outcomes and better mental health.[8] The COVID-19 pandemic, associated economic precarity, and poorer national mental health may ultimately contribute to greater risk behavior and longer-term changes in NCD mortality.

Bringing these observations together, a review of more than 200 studies conducted worldwide found that the median reduction in life expectancy for persons with mental illness was more than 10 years, a doubling of relative mortality rate overall, and more than 8 million excess deaths were related to mental illness annually.[9] This finding reinforces the fundamental observation that mental health is inextricably linked with mortality and needs to be considered in any discussion of mortality in general—and particularly so in the context of the COVID pandemic—in a time of increasing mental illness. AJPH

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Social Justice Is Not the COVID-19 Vaccine Alone: It Is Addressing Structural Racism Through Social Policies That Shape Health

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The first author (V. M. M.) was being interviewed by a reporter, who asked, “Is getting the vaccine social justice?” Perhaps in some measure equitable access to a vaccine can be construed as indicative of social justice. But social justice as a concept is a much more complicated construct.[1] Social justice includes several key principles: fairness in how individuals and society interact, equitable access to public goods and institutions, equitable access to opportunities to improve well-being, and trust that these principles will be followed equitably. A social justice lens brings into sharp focus how structural racism contributes even now to early mortality for many racial and ethnic minorities. Police encounters that are more likely to result directly in violent death for Black men are but one risk.[2] Trauma from actual or anticipated encounters in which such violence is possible is yet another corrosive factor for health. And, of course, there is the disparity in morbidity and mortality risk from COVID-19.[3,4] History underscores the lack of social justice in the United States when it comes to the impact of infectious disease on racial/ethnic minorities.[5] The COVID-19 pandemic is no exception.

COVID-19 IMPACT ON MINORITY COMMUNITIES

Common methods of reducing COVID-19 infection risk that emphasize working from home, using personal protective equipment, social distancing, and isolating potentially infected individuals in separate spaces are more difficult to achieve by racial/ethnic minorities, who are more likely to live in higher density households and communities, work at jobs that require their onsite presence, and lack adequate personal protective equipment.[5,6] During the pandemic, job losses have been disproportionately steeper in racial/ethnic communities and more likely to affect those with fewer financial reserves to carry them through.[7] Food insecurity has severely affected many racial/ethnic minority families.[8] Finally, preexisting and well-documented health disparities affecting racial/ethnic minority communities have also increased the risk of severe illness or death.[4] The losses this pandemic has engendered have not been borne equally.

In this special issue on mortality, *AJPH* touches on some of the ways that a lack of social justice percolates through the landscape of society and permeates our public health infrastructure responsible for recording COVID-19 deaths. It is timely that we do so—more than 600 000 individuals in the United States have died from COVID-19, with American Indians/Alaska Natives, Blacks, and Latinxs 1.9 to 2.4 times more likely on a national age-adjusted basis to have died than non-Hispanic Whites.[9] This racial/ethnic disparity is hard evidence of the toll that structural racism exerts on the lives of some Americans. Yet, many of those who have died from COVID-19 are invisible to the nation. They are often the everyday workers who keep all of us fed or cared for when infirm—essential needs when a pandemic hits. Many of the deceased belonged to families who may include COVID-19 survivors as well. It is important to state that many of the deaths among Blacks, Latinxs, American Indians, and Pacific Islanders are not owing to what they did willingly but to what they could not do despite public health messages.

During this pandemic, essential workers often did not have the option to social distance or mask up. Those who

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were not licensed health care providers working in hospital settings often did not have access to vaccines in the first distribution wave despite their occupational risks. And even when eligible for vaccines, for some the path toward getting those shots sometimes involved mechanisms (e.g., interface with computer systems) that they were less likely to have access to or familiarity with or requirements (e.g., car access only, take a day off from work) that were insurmountable. Public health authorities also have had more trouble keeping track of vaccination rates among racial/ethnic minorities.[10]

So, yes, getting shots in arms is good; it is leading to the end of this pandemic. But shots in arms alone is not social justice. Social justice is recognizing the differential vulnerabilities unmasked by the COVID-19 pandemic and working to eliminate them. Social justice calls for developing policies that will serve to protect all going forward and enforcing existing policies that aim for equity but have been allowed to lapse. Racial and ethnic minorities, low-income individuals, and tribal members died unnecessarily while public health approaches emphasized feasible risk-reduction strategies for those of greater privilege but lacked the vision to create approaches to infection control that would protect equitably. For example, as Feldman[11] notes, the possibility that workplaces were major contributors to the COVID-19 pandemic has been downplayed, perhaps to minimize business disruptions. But studies have documented that a primary contributor to the racial inequalities seen in COVID-19–related infection transmission is workplace exposure among in-person essential workers.[12,13]

Racial/ethnic minorities are more likely than are non-Hispanic Whites to be employed as essential workers in industries in which there have been higher infection rates (e.g., health care, agricultural work, food processing, warehouse work, customer-facing food supply work). As one example, in California, there was a 30% increase in deaths in 10 essential industries over the period of the first 10 months of COVID-19.[12] The highest statewide increase in deaths compared with the previous year was in warehouse and food chain workers. In a second example,[14] evidence from a large grocery store in Boston, Massachusetts, revealed that employees with customer interaction jobs were five times more likely to test positive for COVID-19 antibodies than were those who worked in noncustomer contact positions.

SAFETY NET POLICIES CREATE INEQUITY

One significant policy intervention that could have made a difference in protecting workers and their families equitably during the COVID-19 pandemic is a robust, universal paid sick leave policy at the start of the pandemic. Without paid sick leave, workers in low-wage jobs with little savings—disproportionately Black and Latinx workers—faced considerable barriers to following public health guidelines to social distance and quarantine if exposed. In April 2020, Congress enacted emergency paid sick leave, which temporarily provided 10 paid sick days to workers affected by COVID-19. However, companies with more than 500 employees were exempt from the mandate, leaving more than 68 million Americans—including the more than 2 million essential workers employed by large grocery store chains—without protections.[15] Even for workers covered by the law, the protections expired at the end of the year, just as COVID-19's second wave was beginning.

Paid sick leave's benefits to public health are extensive, are well documented, and shape whether individuals can prevent and receive treatment for diseases with substantial morbidity and mortality. Access to sick leave, for example, reduces the spread of influenza, which, according to the Centers for Disease Control and Prevention, is responsible for between 12 000 and 61 000 deaths in a typical year[16]; amid the pandemic, the provision of emergency paid sick days—even with its gaps in coverage—prevented approximately one case of COVID-19 per day for every 1300 workers who newly had access to leave.[17] And both during and independent of the pandemic, individuals who have access to leave are more likely to be able to go to clinics to receive immunizations, more likely to be able to see physicians for preventive care, and less likely to go to work when they are sick and, hence, inadvertently spread communicable diseases.

Yet the US failure to adopt permanent, paid sick leave at the national level has created significant racial, ethnic, and socioeconomic disparities in coverage, making these benefits more accessible to some workers than others. With no national policy, the United States has largely left the provision of paid sick days up to employers. As a direct consequence, racial/ethnic minority and low-wage workers are disproportionately left out. As just one example, 54% of Latinx workers lack paid sick leave, compared with 37% of non-Hispanic White workers. This gap leaves Latinx workers at higher risk for exposure to COVID-19 and many other illnesses and far less able to receive care early, which has been reflected in much higher case and hospitalization numbers.[18]

Meanwhile, another piece of the safety net has had important gaps. The 1993 Family and Medical Leave Act (Pub L No. 103–3) was designed to exclude workers in small firms, part-time workers, and workers who recently changed jobs from unpaid medical leave. The purpose of these limitations was to reduce burdens on small business, but the consequence was to create exclusions that left millions of Americans without adequate coverage—another opportunity missed for true social justice in public policies. For example, just 29% of Latinx workers, compared with 41% of non-Hispanic White workers, are both eligible and can afford to take unpaid medical leave under the Family and Medical Leave Act.[19]

These structural inequalities in access to sick and medical leave have profound health and economic consequences that go far beyond the current pandemic and exacerbate other health disparities. Workers without paid sick leave are three times more likely to forgo personal health care.[20] Parents without sick leave are also more likely to send their children to school or childcare when the children are ill and less likely to be able to provide care to elderly family members who are sick.[21] Workers without sick leave are also more likely to lose their jobs because of their own illness or medical condition.[22,23] One of the authors (J. H.) first documented marked racial and class disparities in access to sick leave 25 years ago.[24] The question is not whether the lack of sick leave is a clear contributor to health and economic inequality in the United States; nor is it whether the passage of national paid sick leave would benefit all Americans. Both have now been repeatedly documented. The question is whether the United States will finally close the egregious gaps in who is able to care for their own health and that of their family.

Just as the United States is long overdue to ensure that sick leave is available to all regardless of race and class, the United States also urgently needs to fulfill its duty to eliminate structural racism in other social policies. Unemployment insurance gaps are an important example that the pandemic has provided. In addition to workers who lost jobs during COVID-19 because of illness, many became unemployed because of the shutdowns imposed to control the pandemic's spread. As with sick leave, structural inequalities have shaped both the accessibility and the adequacy of unemployment benefits that these newly unemployed persons have had access to. Because of higher barriers to eligibility in states with larger Black populations, White workers were nearly twice as likely to receive unemployment benefits as Black workers when the first wave of pandemic layoffs hit, placing the health and well-being of Black workers and their families at far greater risk.[25] Moreover, the cumulative evidence suggests that this racial variation in benefit accessibility is not by chance: states with larger Black populations also provide lower levels of cash assistance ("welfare"),[26] have been less likely to expand access to Medicaid,[27] and impose higher barriers to the right to vote.[28]

ENACTING EQUITABLE SAFETY NET POLICIES

Solutions are within our reach. In the case of paid sick leave, 181 countries around the world have a national guarantee[29]; the United States is 1 of only 11 countries that does not. Moreover, the enactment of modest paid sick leave policies at the state and local levels, although no substitute for national action, has demonstrated the feasibility and impacts of adopting permanent sick days in the United States. When New York City passed five days a year of paid sick leave, workers who had Medicaid for health insurance—a population with higher proportions of Black and Latinx Americans—began to receive better preventive care for chronic diseases.[30] Likewise, with regard to unemployment insurance, there is no reason that the United States cannot replace and modernize the current patchwork of state policies with national standards that would eliminate racial inequalities in benefit access embedded in the current system. Numerous countries—including others with federal systems of governance—also have nationally funded and administered systems of unemployment insurance.

At its core, building a national safety net that is equally accessible regardless of race, ethnicity, or social class is critical to advancing the fundamental ideal of equal rights that the United States has never fully realized but must do all in its power to rapidly fulfill. Providing sick leave and unemployment insurance are but two examples of many possible remedies that would put us on the road to achieving social justice. A commitment to social justice also demands that we address the panoply of health and social policies—including those related to health insurance, economic support, US Food and Drug Administration rules for shipping harm-reduction supplies, immigration enforcement, and mass incarceration—that have created an outsized burden of the pandemic on racial/ethnic minority communities. US reliance on immigration detention, for example, put thousands of children and adults at high risk for COVID-19 infection because of the infeasibility of social distancing in confinement; the experience of numerous countries elsewhere shows that effective alternatives did exist.[31] Likewise, rates of COVID-19 infections in jails and prisons—which disproportionately house Black and Latinx men because of systemic racism in criminalization, policing, and sentencing—have been more than five times greater than those of the general population.[32] As with the US failure to guarantee sick leave, this institutionalized neglect of the health of marginalized populations both violates basic human rights and threatens the health of everyone. In rural counties with large correctional facilities, for instance, COVID-19 cases spiked as a result of community spread.[33]

The COVID-19 pandemic, like all pandemics before it, has exploited the opportunities we created by allowing structural racism to pervade our approaches to protecting public health. We must use evidence-based approaches to determine the lattice of social and health policies that will create social justice in health for all.[34] It is also critical to investigate data quality standards that will contribute to equitable benefits from public health surveillance. A commitment to social justice demands renewing our efforts to advance equitable policies, approaches, and procedures in how we seek to ensure health for all.

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Ghost in the Machine: The Emotional Gravity of Conducting Mortality Research

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An epidemiology graduate student recently demonstrated to me that analyzing vital statistics carries occupational hazards. Reviewing overdose mortality data, the student was viscerally reminded of childhood experiences precipitated by their father's substance use and undiagnosed mental health issues. In between neat rows of structured data, the father's death reasserted itself, along with the family's trauma. Although the student's passion for public health stemmed from these very experiences, the scholastic environment had not allowed for expression of this identity. Therefore, when distressing feelings arose, there was no antecedent. It was a missed opportunity to support a trainee.

The emotional gravity of working with mortality affects seasoned researchers too. With a few taps, I can securely access tens of millions of death records from my phone. These data weigh heavy in my pocket as I go about my day. After two decades of working with these data, when I duck into a car, I wonder how soon I may end up as a death record in a row. Like many others, I can vividly remember the first time I saw a friend's death record in a data set. (Although ostensibly anonymized, the circumstances were clear.) I caressed the row with my mouse; I left the window open on my desktop for days, feeling his presence emanating through pixels. I do not think these experiences make my research any less objective. Rather, they hold me accountable to a higher power.

I take regular walks through two historic cemeteries flanking my neighborhood. I do not know a soul there; most of the people died before people of my ethnic background were even allowed into the country. No causes of death are mentioned on the tombstones, yet the decorative filigree, monumental regalia, family plot spacing, and epitaphs offer communion across centuries. Why do I feel a sense of calm when walking out of the cemetery but feel unsettled when shutting down my computer after days of analysis? I have come to realize that highly structured death data are vulnerable to emotional truncation. The encoded and medicalized encapsulation suits our surveillance needs, their parsimony implying that these are the only factors that matter. They are not.

Protection of research participants is a standard concern, but less attention is paid to the emotional well-being of analysts. Compassion fatigue and secondary researcher trauma have been described extensively in qualitative research. Sikic Micanovic et al. provide a concise review,[1] and Kumar and Cavallaro present a useful framework.[2] *Qualitative* research emphasizes the investigator's viewpoint and orientation toward the subject matter because the research paradigm fully accepts that such acknowledgment can enrich interpretation. However, the dispassionate façade of *quantitative* research blinds us to analysts' feelings: paradoxically, it is assumed that thousands of death records exert no mental toll. As my personal vignettes suggest, vital statistics data also carry emotional weight.

Emotional danger is defined as negative "feeling states" induced by the research process. This means not just feeling uncomfortable, but also manifesting distress that affects interpersonal relationships.[1] By ignoring emotional impacts, we may be compromising our staff and results. Beyond the beguiling cleanliness of structured data, every data point embodies heartache. However, rows upon rows can lead to inurement. How do we retain our humanity? Qualitative researchers have suggested journaling the research experience and engaging in structured debriefing sessions.[3] Incorporating researcher well-being should be part of research design; we must dispense with the practice of masking emotions for the sake of projecting a professional posture. Personally, I keep photographs on my desk of loved ones who have passed. Sometimes, I light a candle and ask them if I am representing them with fidelity. This is one of my rituals, and I welcome you to share yours. AJPH

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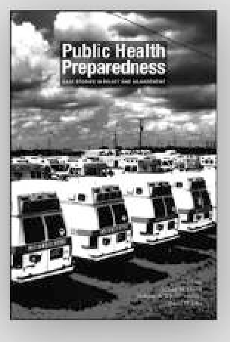

Death Cafés: Where Communities Affirm Grief

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As the United States surpasses 550 000 excess deaths from COVID-19, the impact of these fatalities is especially salient. COVID-related deaths will likely accelerate a years-long trend in declining "working age" life expectancy.[1] Individuals who are left, particularly racial and ethnic minorities, are shouldering the burden of losing their elders and cultural knowledge bearers, multiple family members, and others suddenly and without closure. Critically, these same communities must grieve during the pandemic, which has cumulatively stripped them of economic sustenance as well as their traditional mourning and burial practices.

The downstream effects of these large-scale disruptions in grieving rituals may be persistent and affect future generations through higher health care costs, mental health burdens, loss of community and family supports, and stunted productivity.[1] More immediately, bereaved persons may suffer distress arising from survivor's guilt as well as the effects of prolonged and traumatic grief.[2] Creating space for communal expressions of grief is thus central to the public health needs of the present generation.

Accessible structures that can facilitate communities coming together at a localized level are death cafés. Death cafés are free-of-cost gatherings at which locals—often strangers—share their perspectives and questions about mortality. Distinct from therapy or bereavement groups, death cafés encourage wider participation of individuals who are curious and may have no personal experience with death alongside people who see death daily at work. The cafés fit within the death-positive movement that aims to reduce the stigma behind death.

The demand for and interest in these groups have rapidly increased in light of COVID-19,[3] and organizers have accordingly transitioned to virtual gatherings. Death cafés engage people who are diverse across race and ethnicity, gender, age, and experiences with death in group-directed discussions that meet the current needs of individuals in their immediate contexts.

Even young adults are attending death cafés to process the premature deaths of others their age.[4] Hospitals and nursing schools have adopted these spaces to prevent burnout and share resources on palliative care as health care workers navigate their own losses while taking on caregiver roles with patients.[5] Health care providers experienced unprecedented deaths in a short period of time in the early days of COVID-19. Churches and synagogues, in the face of changes to their traditional funeral services, are also hosting death cafés online for their congregations. Inspired by death cafés, Chinese Americans are holding group discussions in Mandarin about end-of-life care.[6]

As public health calls for collective meaning-making practices at national and local levels to support resilience after mass losses from COVID-19,[2] death cafés may be one such approach. Social critiques of ways in which death is handled by the media, our death determination practices, and the practice of medicine can leave some individuals feeling unresolved grief, and some death café participants feel a responsibility to contextualize their grief within current failings.[7] For example, a woman whose disabled grandfather died after being denied medical care asked in one death café why some lives are deemed more dispensable than others.

Death cafés offer an intimately scaled and emotionally tangible approach to collective grief and discourse given the limitations imposed by the COVID-19 pandemic. In turn, they may bring us closer to building equitable and health-promoting institutions and communities that can heal together. Although these gatherings do not replace the urgent gains we must make in addressing inequities in mortality and disparities in grief burdens that already-overburdened communities carry, death cafés can offer a path forward by inviting life-affirming practices that arise from grief. AJPH

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Prioritizing Improved Data and Surveillance for Suicide in the United States in Response to COVID-19

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COVID-19 and the precautionary measures put in place to prevent its spread have given rise to concerns about second-order mental health effects, including potential increases in suicide. Researchers have pointed out historic associations between the individual and combined effects of economic stress, social isolation, and decreased access to community supports on suicide rates.[1] The United States has also observed increases in the sale of firearms[2] and alcohol[3]—factors known to exacerbate suicide risk. After the May 2020 release of a video of George Floyd's death, there were reports of elevated distress among Black and African American people,[4] which raised further concerns.

In response, the National Action Alliance for Suicide Prevention convened representatives from private and public sectors to create the Mental Health & Suicide Prevention National Response to COVID-19 (National Response). The first goal of the National Response was to identify strategic priorities to transform mental health awareness and suicide prevention nationwide. These priorities were published online in September 2020 at www.nationalmentalhealthresponse.org. This editorial discusses the fourth of these priorities: "Establish near real-time data collection systems to promptly identify changes in rates of suicide, overdose, and other key events, and of clusters or spikes in these outcomes." We describe how the National Response has crafted a path forward for achieving the goal of near real-time mortality data with seven specific calls to action. Although this editorial focuses on mortality data, the priority area also emphasizes the importance of near real-time data on nonfatal suicide-related events (i.e., suicide attempts), with more information available at www.nationalmentalhealthresponse.org.

THE IMPORTANCE OF NEAR REAL-TIME MORTALITY DATA

Mortality surveillance is critical for identifying the emergence of new and deadly diseases, monitoring trends in preventable deaths, raising awareness of fatal health conditions, and identifying strategies for preventing additional deaths. With national mortality data currently released 13 months or more after the end of a calendar year, the nation's ability to accomplish these goals with existing data structures is limited.

The COVID-19 pandemic has illuminated problems with suicide surveillance in the United States. Data on COVID-19 mortality rates were being tracked and published online by counties, states, and territories. Private enterprises such as The COVID Tracking Project and Johns Hopkins University were then aggregating the data and presenting them to the public in near real-time. However, policymakers had no comparable data available on other health outcomes, such as changes in suicide rates, that might result from the public health measures put in place to prevent the virus's spread. In the absence of such data, decision-makers were forced to make inferences about the relative impact of public safety measures, many of which were problematic. For example, some researchers produced nonvalidated extrapolations of the forecasted number of excess suicides based on past recessions.[5] No population-level information on trends in rates of intentional self-harm (including suicide attempts) could be tracked from emergency department syndromic surveillance data. Media reports on increases in call volume to the Disaster Distress Helpline capture calls about mental health and suicide as well as other issues (e.g., housing, financial), but we are unaware of publicly available data on use of the National Suicide Prevention Lifeline.

THE CALLS TO ACTION

The National Response has identified seven priorities that, if adopted, could improve monitoring and tracking suicides so that the information can be used for near real-time decision-making and targeted interventions.

> *Call to Action 1.* Increase funding for the public health data infrastructure at federal, state, territorial, and local levels.
>
> *Call to Action 2.* Fund research on how to produce more timely assessments of suicides.
>
> *Call to Action 3.* Track and report survival as a patient-centered outcome for individuals with mental health and substance use issues and in relation to key index events such as emergency department presentation for suicidality or overdose and discharge from inpatient mental health and substance use treatment.
>
> *Call to Action 4.* Mandate universal documentation of external cause of injury (e.g., deliberate self-harm, accident, assault) for all emergency department visits and hospitalizations involving injury.
>
> *Call to Action 5.* Enhance the scope of data collected in death investigations to include information on sexual orientation, gender identity, and military and veteran status, as well as to improve the quality of data collected on race and occupation and industry.
>
> *Call to Action 6.* Coordinate interaction between the Action Alliance and states, territories, and local jurisdictions to develop standardized, defensible ways to use data from existing (or newly created) sources in program planning, surveillance, outcome assessment, and policymaking
>
> *Call to Action 7.* Create a National Response data dashboard that pulls together timely data feeds from relevant existing sources on fatal and nonfatal suicide events and related measures.

Call to Action 1

The COVID-19 pandemic has illustrated the threat posed by illness and disease and the importance of surveillance for early identification and monitoring. There are currently more than 2000 death investigation jurisdictions in the United States that vary by geography (state, county, or district) and oversight (coroner, medical examiner, or a combination thereof). This structuring leads to variation in—and presents challenges to improving—the quality and timeliness of mortality data.[6] Similarly, 57 separate jurisdictions across the US states and territories report mortality data to the national level, each with distinct practices and policies. The data systems on which many of these jurisdictions rely are antiquated: "sluggish, manual processes—paper records, spreadsheets, faxes and phone calls—[are] still in widespread use" that may result in "delayed detection and response to public health threats of all types."[7]

The National Response has prioritized increased funding for the public health data infrastructure, echoing the recent "Data: Elemental to Health" campaign spearheaded by the Council of State and Territorial Epidemiologists (CSTE).[7] CSTE calls for Congress to secure $1 billion over the next decade to modernize disease surveillance systems. There is opportunity for private sector involvement, by providing technological solutions at discounted costs to enhance efficiencies and share advances in data science, to improve the collection and analysis of mortality data.

Call to Action 2

Suicide is one of five manners of death listed on death certificates. Classifying a death as a suicide requires evidence that the cause of death (injury) is self-inflicted and that the individual intended to die as a result of the act. Death investigations for all injurious deaths take longer than other causes of death. In the case of suicide, only 50% of suicides are officially categorized within two months after the week of the death, 71% at three months, and 93% at six months, and almost all are coded by 10 months.[8] This is one of the reasons why annual national suicide data are typically only available 13 months or more after the end of a calendar year.

There is known variation in the time it takes to make a death determination by method of injury,[8] but there may also be variation across death investigation jurisdictions. Oregon, for example, publishes monthly provisional year-to-date mortality data on manner of death (including suicide) by county, and preliminary investigations of suicides during the COVID-19 pandemic have been published for Maryland,[9] Massachusetts,[10] and Connecticut.[11] The National Response advocates for researchers to identify additional jurisdictions collecting and presenting near real-time suicide mortality data, the impetus leading to the presentation of these data near real-time, barriers encountered, and data limitations.

"Nowcasting" is widely used in economics to predict the present, near future, and recent past of an economic indicator (e.g., gross domestic product growth) in the absence of complete information. Nowcasting attempts to measure events in real-time as opposed to forecasting, which uses historical data to project future trends. Existing data systems that might be useful in nowcasting suicide rates include health system data on nonfatal suicide events, data collected by emergency medical services, emergency department syndromic surveillance systems, and crisis lines. Data from other sources, such as Internet search terms and firearm or alcohol sales, may also be useful for nowcasting. Preliminary work by the Centers for Disease Control and Prevention suggests that weekly nowcasting that applies machine learning to multiple streams of data may provide accurate estimates of suicide.[12] Further research is needed to identify which data, or combinations of data, can be used to produce and validate accurate approaches to suicide nowcasting models. This research would also require public and private sector entities that own or manage useful data to make them available to researchers for nowcasting purposes.

Call to Action 3

Health care settings are critical for identifying and intervening with persons at risk for suicide. Data from the Mental Health Research Network estimate that 30% of persons who die by suicide have a health care visit in *the week* before their death—6.5% have an emergency department visit, 16.3% receive outpatient care, and 9.5% receive primary care. These rates are higher than among matched controls.[13] In California, individuals presenting to emergency departments have elevated suicide mortality rates in the year after being seen relative to demographic-matched controls.[14]

Call to Action 3 echoes Recommendation 1.8 of the Interdepartmental Serious Mental Illness Coordinating Committee's (ISMICC) 2017 report to Congress. By linking health care delivery data to mortality data, health systems can identify settings and patients with elevated suicide risk and direct suicide prevention services there. However, this approach requires addressing technical and resource barriers (among health systems and death data systems) as well as legal (e.g., Health Insurance Portability and Accountability Act) and policy barriers, including at least one hospital accreditation issue. Specifically, the suicide of any patient within 72 hours of discharge from a hospital, including an emergency department, is considered by The Joint Commission to be a "sentinel event" that requires investigation within a year of its occurrence. Health systems are likely to uncover more events when they begin to link data, which may be a disincentive for conducting routine medical record and mortality data linkage.

Call to Action 4

Self-inflicted nonfatal injuries and poisonings that require medical attention are identified in health records using a combination of injury diagnostic codes, which identify the nature of the injury and body part injured, and "external cause of morbidity" codes, which describe the intent of injury—accidental, deliberate, or of undetermined intent—as well as the mechanism by which the injury occurred. However, in more than half of US states, external cause codes are not routinely listed in a medical record.[15] Without enforceable mandates to do so, many health systems are not capturing data on intentional self-harm, resulting in an underestimate in national trends. This call to action is also recommended by The President's Roadmap to Empower Veterans and End a National Tragedy of Suicide (PREVENTS) Task Force.

Call to Action 5

In addition to monitoring trends of suicides in the general population, death investigation data can be used to identify subpopulations with elevated risk, provided that such data are accurately recorded during death investigations. Although population-based research suggests elevated rates of suicide attempts among lesbian, gay, and bisexual adults[16]; youths[17]; and transgender populations,[18] Los Angeles, California, is the only jurisdiction that requires medical examiners to systematically document information on sexual orientation and gender identity at the time of death.[19] Standard death certificates ask whether the decedent was ever in the US Armed Forces but do not specify whether the decedent was a veteran, currently in the military on active duty, or a member of the National Guard or Reserves. This documentation does not require that the data be included on the official death certificate, only that the information be systematically collected, reported, and recorded in data systems that reflect results of death investigations.

The quality of data for certain data fields on the death record must also be improved. Some deaths caused by drug self-intoxication have manner of death coded as "accidental," but "suicide" may be more appropriate or, as advocated by Rockett and Caine,[20] self-injury mortality may be needed as a new code on death records to enumerate all such deaths together. In fact, there are overlapping risk profiles in persons who die by suicide and persons who die by "unintentional" overdose.[14] Furthermore, only 51% of decedents who previously identified their race as American Indian or Alaskan Native had race correctly coded on their death certificates (most are misclassified as White), which should be improved.[21] Finally, identifying industries and occupations for elevated suicide risk (and thus, targeted attention) would also be useful, but autocoding procedures are not yet available to convert these text fields into numeric codes.[22]

Call to Action 6

Most suicide prevention occurs locally. Prompted by the 2001 National Strategy for Suicide Prevention, every state currently has a statewide suicide prevention plan. Additionally, states, territories, tribal communities, and cities support suicide prevention activities via grant programs such as the Garrett Lee Smith Memorial Youth Suicide Prevention Program and initiatives such as the Governor's and Mayor's Challenges to Prevent Suicide Among Service Members, Veterans, and their Families. These initiatives should be empirically based, include surveillance as part of their efforts, and be evaluated with data. This point is emphasized in the Suicide Prevention Resource Center's State Suicide Prevention Infrastructure framework, which provides states with recommendations for strengthening community suicide prevention programming.[23] Evaluations of Garrett Lee Smith grantees' prevention initiatives provide examples of how mortality data can be used to understand the effects of these programs on youth suicide rates.[24]

Call to Action 7

The COVID-19 pandemic has made clear the importance of using data from multiple sources in a single location to provide a more comprehensive picture of the burden of disease. Online tools, such as the COVID-19 Dashboard produced by Johns Hopkins, are used by policymakers, the media, researchers, and the public for up-to-date information on disease incidence, prevalence, case fatality, and mortality.[25] A dashboard for suicide could similarly provide near real-time information on morbidity and mortality, with additional data on geographic variation in suicide trends, rates in specific populations, and method of death. Colorado's "Suicides in Colorado" data tool for communities is a useful prototype. However, a national dashboard could be expanded even further to provide data on nonfatal suicide-related events such as suicide attempts seen at emergency departments, suicide-related mobile crisis team responses, and call volume to crisis lines.

CONCLUSION

Limitations in the morbidity and mortality surveillance infrastructure have hindered the nation's ability to understand the effects of the COVID-19 pandemic on suicide risk. This has direct implications for emergency resource decision-making and hinders policymakers' ability to ensure that adequate resources (including monetary and programmatic) are maintained or newly delivered to communities and populations experiencing heightened suicide risk. These limitations are not new; many of the calls to action echo recommendations made previously by groups such as the CSTE, ISMICC, PREVENTS, and the Action Alliance's Data and Surveillance Task Force. They are also built upon existing efforts already under way, including the National Center for Health Statistics Rapid Release mortality dashboard. The COVID-19 pandemic has created a sense of urgency that we have not seen before, and the National Response provides a forum to amplify previous recommendations and identify new ones. These seven calls to action create a pathway toward improving the timeliness and use of mortality data that not only responds to conditions created by the pandemic but also, if pursued, is likely to create a stronger and more supportive mental health and suicide prevention surveillance infrastructure. AJPH

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The Mask of Unequal Health and Excess Death: A Reality

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In Edgar Allan Poe's 1842 gothic tale, "The Mask of the Red Death: A Fantasy," a nobleman and his wealthy friends attempt to escape a horrific plague by hiding out in a castle-like abbey dancing the night away, until death in the form of a masked figure systematically stalks them all down. The reality in our current pandemic is quite different as many in the middle and upper classes *have* been able to flee COVID-19 by staying home to work, ordering necessities to be delivered, or retreating to their second rural or beach homes. Poe's story demonstrated that a plague death was not escapable, but we know from other pandemics, not just this current one, that race, class, gender, and immigrant status always affect who survives or does not.[1] What do we do about this?

We know that nonpharmaceutical interventions matter in saving lives and preventing illness on both the personal and collective level, as a 2007 historical analysis of the 1918–1919 flu pandemic showed. Officials used this report over and over again in the current pandemic to make the argument for all the school and commerce closings that led toward "flattening the curve" of rising infections.[2] In the same year as the historical analysis appeared, a different report by bioethicists established a set of social justice principles that argued for identifying so-called disadvantaged groups who would be more harmed by a pandemic, engaging them in planning, and identifying their special needs.[3] The Trump administration barely took the lessons from the historical analysis and certainly ignored the concern with social justice.

Most of us in public health knew systemic racism and health disparities would make differential illness and death rates happen. At first it was hard to prove this because not all states were keeping statistical data by race.[4] Much of this could have been expected had we learned more from how to use the data from the 1918–1919 flu pandemic.[5] However, the data are not so clear from that experience, and many Southern states did not keep vital statistics on Black Americans until the 1920s. Historian Vanessa Northington Gamble argued that the 1918 flu pandemic caused *fewer* deaths than expected among Black Americans, at least in hard-hit Philadelphia, although she notes that conclusion is uncertain because of probable undercounting. The caring work by Black health care professionals and lay women, in particular, made a difference in outcomes, and segregation may have served as "de facto quarantine." But none of this changed the racism that affected life chances after the pandemic.[6]

As our modern-day lynching photos in the form of the endless videos of Black deaths at the hands of the police make clear, there is almost a pornographic expectation that people of color will continue to die in various ways out of proportion to their numbers in the population. In that sense, higher Black mortality has come be expected and, alas, accepted. If we take seriously the concept that racism is the number one public health problem, we have to do more than what happened after the other major pandemic. This is our time.

We have to follow the dictates of the 2007 bioethics report and consider what we do now. Pressure on legislatures, the federal government, the courts, and the giant health conglomerates to focus on population health and equity has to happen. If public health is not based on social justice, we will end up accepting that excess Black mortality is somehow "normal." And if we do not do this in a way Poe will be right: we cannot all hide forever, and an unnecessary viral death will eventually stalk everyone. AJPH

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Counting for Accountability in a Time of Catastrophe: COVID-19 and Other Deaths, Cohorts, Color Lines, and Dollar Signs

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Counting our dead—with accuracy and for accountability—is core to public health. For COVID-19, can we do right by those harmed and hold accountable those who have exacerbated the pandemic's devastating—and inequitable—lethality?

The deluge of COVID-19 data in the United States has been both astounding and inadequate. Between myriad rapidly constructed public health agency data dashboards, news media data-driven visual and in-depth reporting, and citizen science Web-based COVID-19 trackers to highlight inadequately reported risks by racialized groups, gender, and occupation, we are awash in both data—and exposed data gaps.

But will this data frenzy let us tally the true toll of COVID-19? Motivated by my own work wrestling with COVID-19 data for health justice in the United States,[1,2] I raise three urgent concerns that have global implications.

INEQUITABLE UNDERESTIMATES OF COVID-19 MORTALITY

To the extent that classification of COVID-19 deaths depends on access to being tested or hospitalized for COVID-19, in the US context this will lead to systematic undercounts of COVID-19 deaths among workers in low-wage jobs who lack health insurance and among elders who lack access to adequate care. Together, such undercounts will be concentrated among the Black, Indigenous, and Latinx populations. Analyzing excess deaths helps, but does not resolve, this problem.[2]

Related, if people who survive COVID-19 develop post-acute sequelae of SARS-CoV-2 infection (i.e., experience persistent symptoms and poor health after acute COVID-19 illness) or COVID-19–related organ damage, will their eventual death certificates list COVID-19 as an underlying or significant contributing cause of death?—or omit it altogether? If the answer depends on quality of medical records, socially biased undercounts are bound to occur.

INEQUITABLE IMPACTS ON OTHER CAUSES OF DEATH

COVID-19 is already disproportionately killing people diagnosed with cancer, cardiovascular disease, and diabetes—all diseases that are marked by inequities. If this results in drops in deaths for these other causes, will this lead to facile interpretations implying that rates and inequities in these other causes of death are "declining"?

Conversely, what about selection effects induced by COVID-19? Will those left alive (comprising the numerators and denominators for other outcomes) skew toward better health profiles? Will it be recognized that any contingent gains in non–COVID-19 mortality rates and reductions in inequities come at the expense of decimation by COVID-19? More broadly, how will socially patterned birth cohort effects, conditioned on people's chronological age during the brutal first years of the pandemic, affect future mortality rates and their inequities?

INEQUITABLE MORTALITY IMPACTS OF PANDEMIC POLITICS

Consider too the mortality impacts of the profoundly racialized economic and social devastation wrought by the pandemic above and beyond COVID-19 mortality inequities[1,2] Will analyses address or ignore the causal role of wealthy elites, including politicians and their billionaire enablers, who have prioritized profits over people, stoked COVID-19 denialism, and opposed coherent, compassionate, and equitable COVID-19 policies?[2]

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I fear the latter. The overwhelming neglect of the continued impact of Jim Crow on contemporary US mortality rates starkly reveals how individualistic whitewashing (aptly encoding White supremacy) can render institutional and individual memory short, even as embodied risk lives on. The mass protests against structural racism in 2020, sparked by horrific police violence in conjunction with COVID-19 inequities[2]—and echoed in the equity declarations of the new Biden–Harris administration—demand better.

Minimally, a permanent asterisk—and corresponding footnote caveat about data limitations and sociopolitical context—should be affixed to any mortality estimate potentially affected by the COVID-19 pandemic. Beyond this, any true reckoning of the COVID-19 pandemic's toll, both current and forthcoming, must have at its core the entwined impacts of color lines and dollar signs. Anything less would be a betrayal of the public trust that public health must earn. Time to step up and start implementing accountability science for health justice now! AJPH

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A National Framework to Improve Mortality, Morbidity, and Disparities Data for COVID-19 and Other Large-Scale Disasters

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Timely and accurate data on COVID-19 cases and COVID-19–related deaths are essential for making decisions with significant health, economic, and policy implications.

A new report from the National Academies of Sciences, Engineering, and Medicine proposes a uniform national framework for data collection to more accurately quantify disaster-related deaths, injuries, and illnesses.

This article describes how following the report's recommendations could help improve the quality and timeliness of public health surveillance data during pandemics, with special attention to addressing gaps in the data necessary to understand pandemic-related health disparities. (*Am J Public Health*. 2021;111(S2):S93–S100. https://doi.org/10.2105/AJPH.2021.306334)

Timely and accurate counting and attribution of COVID-19 cases and COVID-19–related deaths are essential for making decisions with significant health, economic, and policy implications. For instance, as states consider reopening schools and businesses, there has been considerable attention to developing metrics that are science-based, objective, reliable, and accurate. Reflecting such needs, multiple public and private organizations now produce a variety of COVID-19 data dashboards and reports. Yet, the availability of so much data presented in different ways can create confusion, and while there may be good rationales for using differing metrics for differing purposes, the lack of uniform standards for data collection and reporting limits analyses complicates interpretation and can even facilitate political manipulation of these data.[1]

Analysts have reviewed the interpretation and pros and cons of various COVID-19–related metrics[2] and proposed a common set of metrics.[3] In this article, we focus on quality and collection and standards for the data underlying these proposed common metrics. A new report from the National Academies of Sciences, Engineering, and Medicine (NASEM) proposes an enterprise approach to implementing a uniform national framework for data collection to more accurately quantify disaster-related deaths, injuries, and illnesses.[4] This article describes how following the report's recommendations could help improve the quality and timeliness of public health surveillance data during pandemics, with special attention to addressing gaps in the data necessary to understand pandemic-related health disparities.

There are 2 main approaches to assessing pandemic casualties, and each has different strengths, weaknesses, and appropriate uses. One is to count individuals who die or become ill and determine whether each death or illness can be directly or indirectly attributed to the pandemic. The other is to estimate casualties by using statistical means, either through sampling methods or by examining excess observed compared with expected illnesses or deaths. This article explores challenges and opportunities related to each approach and then focuses on how each can be used to better examine the role health disparities play in the COVID-19 pandemic. The focus on disparities is important, as accurate ascertainment of health disparities attributable to disasters has historically been challenging, in part because of the failure to take into account the interconnectedness of risks posed by a disaster, in this case the COVID-19 pandemic, and those posed by social determinants of health.[5]

CASE COUNTS FROM PUBLIC HEALTH SURVEILLANCE SYSTEMS

The most common source of case count data is when those diagnosing a "case" notify public health authorities, who then use this information primarily to help control the outbreak—for example, by tracing contacts and quarantining those who might be infected.

The accuracy of case reporting depends on many factors, including patients presenting for care, availability of testing, accurate and stable case definitions, and consistent adherence to reporting standards. Declines in diagnosis and reporting tend to occur at every step in the process and, as a result, the number of officially recorded COVID-19 cases in the United States almost certainly underestimates the true number of infections, perhaps dramatically.

Epidemiologists refer to the fact that only a fraction of infected individuals seek care, are diagnosed, and are reported as the "iceberg effect." This is a common phenomenon, and undercounts derived from case reporting should not be regarded as an attempt to hide the full extent of the pandemic, but it provides reason for cautious interpretation of case-count data, especially from early in the pandemic. For example, Holtgrave et al. demonstrated this effect during the height of the COVID-19 outbreak in New York State; they also found that rates of testing and diagnosis varied widely by race and ethnicity.[6] For example, 6.5% of infected Hispanic adults were diagnosed compared with 11.7% and 10.1% of non-Hispanic Whites and Blacks, respectively. On the other hand, Hispanics and Blacks who were infected were more than twice as likely to be hospitalized compared with infected Whites.[6] These data illustrate that certain population subgroups may be disproportionately represented (or underrepresented) in case-counting processes. Reese et al. used a similar approach to extrapolate from case counts to more complete estimates of COVID-19 illness and hospitalizations.[7]

Early in 2020, the national health system's capacity to mount an effective pandemic response was very limited, and tests were only given to individuals who were strongly suspected of being infected because of symptoms or contact with infected individuals. As testing capacity grew in April, May, and June, so did the number of positive results. During the surge in cases in the South and West in June and July, shortages of testing resources and delays in obtaining results emerged, probably recreating undercounts of cases. Notably, a state-by-state analysis in *Stat News* showed that in 26 of the 33 states in which cases increased between mid-May and mid-July, the case count rose because there was actually more disease, not because there was more testing.[8]

Inadequate testing capacity can have a disproportionate impact on undercounting of cases in underserved communities. There are limited data on this, but multiple press reports of financial and other barriers to testing in the summer of 2020, as well as companies arranging for their own employees to be tested, suggest that sociodemographic disparities exist. For example, Kim et al. found that non-English speakers in Seattle, Washington, were overall less likely to have completed testing compared with English speakers (4.7% vs 5.6%), though the proportion tested varied across language groups.[9] Lewis et al. investigated disparities in COVID-19 incidence, hospitalizations, and testing by area-level deprivation in Utah and found that individuals living in areas suffering the highest level of deprivation were approximately 30% more likely to have been tested than those living in areas with the lowest level of deprivation.[10] The number of cases, however, was approximately 3 times higher in the highest versus lowest areas of deprivation such that those living in the areas with the highest level of deprivation were substantially less likely to have been tested, after adjustment for infection rates.

As is often the case in natural disasters, the accurate ascertainment of disparities based on case-count data can be challenging because of the interconnectedness of risks facing underserved communities. Furthermore, because case data are collected primarily for operational purposes such as contact tracing, social determinants of health data are often not collected. As a consequence, race and ethnicity are often the only demographic data available on public health Web sites. The passage of the Coronavirus Aid, Relief, and Economic Security Act (CARES Act; Pub L 116–136) on June 4, 2020, required laboratories to collect demographic data (race, age, ethnicity, gender), but implementation did not occur until August 1, 2020.

Compounding these problems, in the initial phase of the pandemic, testing was largely limited to fixed health facilities—hospitals and clinics—that are, by definition, less accessible to underserved populations. The suspension of public transportation exacerbated this inaccessibility and presumably contributed to many Blacks and other minorities presenting in more advanced

COVID-19 disease states at hospitals.[11,12] These factors may help explain subsequent disparities in mortality.

To address testing limitations, the "test positivity rate" (the proportion of tests performed that return a positive result) has emerged as a popular metric to guide COVID-19 decision-making. But this, too, has limitations. In particular, through the summer and fall of 2020, as testing was promoted and drive-through test sites became available, increasing numbers of low-risk individuals were tested. The implementation of frequent—sometimes weekly—testing programs in some workplaces further expanded the denominator of the test positivity rate. An increasing variety of testing methods with varying sensitivity and specificity also became available. These changes in test availability over time, as well as disparities in access to testing, can affect both the size and the composition of the numerator and denominator of the test positivity rate in ways that might not accurately reflect transmission of COVID-19 in the population, so this indicator should be used with caution.[13]

USING VITAL STATISTICS DATA TO COUNT COVID-19 MORTALITY

An alternative source of case data is the vital statistics system, based on death certificates. These are completed using different definitions and processes than public health surveillance. For instance, while people who die of COVID-19 lung disease will almost certainly be recorded as a death from COVID-19 on the death certificate, categorizing someone with mild COVID-19 who suffers a fatal myocardial infarction is less clear. Guidance issued by the National Center for Health Statistics (NCHS) in early April 2020 said that if COVID-19 played a role in a death, it should be specified on the death certificate either as the underlying cause of death or as "probable" or "presumed," even if testing was not done.[14] However, this guidance has been contentious—it might not be interpreted the same nationwide, and this variation could lead to discrepancies in recording for different populations.

While published studies have yet to examine this issue, it seems likely that inaccurate attribution of cause of death occurs more often in underserved subpopulations. These groups disproportionately suffer from comorbidities such as hypertension and diabetes, which are known to pose increased risks for clinically progressive COVID-19 manifestations, but which may also be identified as the cause of death on the death certificate instead of COVID-19.

IMPROVING DATA BASED ON CASE COUNTS

The data underlying COVID-19 metrics based on case counts are the result of actions and reports by a multitude of health care providers, public health agencies, and others working through public and private systems, often operating independently, and designed for disparate purposes. Improving the resulting data will require a coordinated approach. Thus, the NASEM recommends that the Department of Health and Human Services adopt and support the use of a uniform framework for assessing pandemic-related mortality and morbidity by state, local, tribal, and territorial entities; public health agencies; and death investigation and registration systems. To implement this uniform framework nationally, NCHS in conjunction with state and local vital records offices, medical certifiers, and all relevant professional associations should jointly adopt and apply this framework to practice, including the routine use of uniform case definitions and data collection, recording, and reporting practices (recommendation 2-1[4]).

The NASEM also recommends that the Centers for Disease Control and Prevention (CDC) lead an enterprise-wide initiative to strengthen existing death registration systems to improve the quality of pandemic-related mortality data at state, local, tribal, and territorial levels. Some actions can be undertaken immediately, including

- NCHS funding and support for the transition of the remaining states and territories with paper-based death registration systems to electronic death registration systems and
- NCHS and state registrars requiring that electronic death registration systems adopt standard improvements such as automated and uniform alert flags, prompts, drop-down options, and decision-making support for use by medical certifiers when entering data into a death record in both a routine and just-in-time capacity as well as geocoding of deaths at the community level (recommendation 3-1[4]).

Because of the centrality of public health case reports, there is more information on COVID-19 morbidity than is the case in many natural disasters. Yet some potentially useful sources of information, especially electronic health records, are being underutilized for tracking COVID-19 morbidities. Even simple data on hospitalized cases and the availability of beds and other resources come from different sources, and national systems for collecting and disseminating these data have been controversial. To improve the quality and utility of morbidity data, the CDC should lead a collaborative effort to endorse a common core set of COVID-19–related morbidity data for implementation in all electronic health record systems as well as public health surveillance systems (recommendation 3-2[4]).

POPULATION ESTIMATION METHODS

An alternative approach for understanding the total health impact of the pandemic is to use population estimation methods, such as population sampling or estimates of excess mortality and morbidity. In some applications (e.g., estimates of excess deaths), these methods cannot distinguish which specific individuals would have survived in the absence of the pandemic from those who would have died during the period regardless. Yet, compared with case-counting methods, population estimation methods can often provide more accurate estimates of the total impacts of a disaster, including mental health outcomes and social consequences.

USING SAMPLING TO ASSESS MORBIDITY AND MORTALITY

While case-counting methods are sometimes said to be more rapid than population estimation methods, COVID-19 has demonstrated the value of ongoing surveillance efforts, such as CDC's Outpatient Influenza-like Illness Surveillance Network (ILINet), which provides near-real-time data on visits for influenza-like illness (ILI; fever and cough or sore throat) reported by approximately 2600 primary care providers, emergency departments, and urgent care centers throughout the United States. Because COVID-19 illness often presents with ILI symptoms, ILINet is being used to track trends and allows for comparison with previous influenza seasons. Also, the National Syndromic Surveillance Program, which tracks emergency department visits in 47 states, has been extended to include COVID-19–like illness (fever and cough or shortness of breath or difficulty breathing). Figure 1 displays the ILINet and National Syndromic Surveillance Program data through October 10, 2020, reflecting a peak number of cases in early April and a reemergence in June and July.[15]

Another alternative to traditional public health surveillance is to use information collected from representative samples of individuals. This includes seroprevalence surveys of individuals in the population, which can determine the percentage of people in a community infected with severe to acute respiratory syndrome coronavirus 2 (SARS-CoV-2), the virus that causes COVID-19. For example, Rosenberg et al. analyzed a statewide convenience sample of New York State grocery store customers and estimated that the antibodies to SARS-CoV-2, through March 29, 2020, was 14%.[16] This rate varied substantially by geographic area (reaching 24% in New York City) as well as race and ethnicity. They also estimated that only 8.9% of individuals infected during this period were diagnosed, and that this fraction varied from 6.1% of individuals aged 18 to 34 years to 11.3% of those aged 55 years or older.[16] Population-based seroprevalence studies have been conducted in California,[17,18] Indiana,[19] Georgia,[20] and other countries (e.g., Iceland,[21] Spain,[22] and Geneva, Switzerland[23]).

Another alternative is to analyze blood samples obtained for other clinical assessments. Bajema et al., for instance, tested residual blood samples submitted for routine screening or clinical management from July 27 to September 24, 2020, from 177 919 individuals from all 50 states, the District of Columbia, and Puerto Rico. Their analysis shows how seroprevalence varied both geographically and temporally during this period.[24]

Surveys are useful in understanding the consequences of COVID-19, both in general and in different sociodemographic groups. For example, the Census Pulse survey was designed to deploy quickly and efficiently, collecting data to measure household experiences during the pandemic. For instance, in September 2020, this survey found substantial disparities in food insufficiency (the share of households that sometimes or often did not have enough to eat in the past 7 days). The proportion of houses reporting food insufficiency varied from 18% of non-Latino Blacks and 16% of Latinos to 7% of non-Latino Whites and Asians.[25] Food insecurity has an impact on nutritional status, which, in turn, can suppress the immune system, rendering it less effective to mount a response against infectious agents including SARS-CoV-2.

USING EXCESS MORTALITY AND MORBIDITY METHODS

Excess mortality calculations, which are based on comparing the observed number of deaths in the pandemic period to an earlier time, include both direct and indirect deaths and therefore typically provide the most complete estimates of COVID-19's impact. Figure 2 illustrates this approach using weekly mortality data from the United States from January 2020 through March 2021. The total number of deaths each week includes both those classified as COVID-19–related deaths in light gray and all

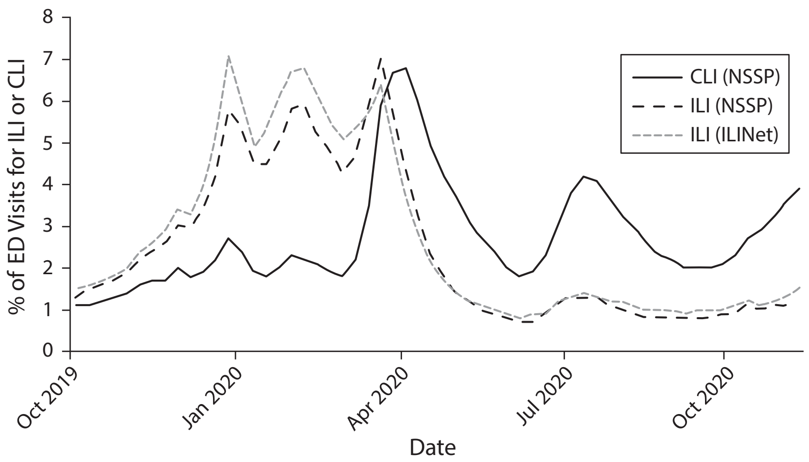

FIGURE 1— **Percentage of Outpatient and Emergency Department (ED) Visits for Influenza-Like Illness (ILI) and COVID-19–Like Illness (CLI): United States, September 29, 2019–October 10, 2020**

Note. ILINet = influenza-like illness surveillance network; NSSP = National Syndromic Surveillance Program.
Source. Authors' calculations based on Centers for Disease Control and Prevention data.[15]

others in dark gray. Expected deaths are represented by the line, calculated by CDC based on mortality data from 2013 to 2019.[26] Excess deaths are calculated as the difference between the height of the bar and the line.

Examining the period between March 1, 2020, and January 2, 2021, Woolf et al. estimated 522 368 excess deaths in the United States, 23% more than officially reported. Of the estimated excess, only (72%) were attributed to COVID-19.[27] Rossen et al., using a similar approach, estimated that 299 028 excess deaths occurred from late January through October 3, 2020, with only 198 081 (66%) of these deaths directly attributed to COVID-19. The largest percentage increases were seen among Hispanic or Latino persons, with the number of deaths in April and August approximately double the numbers in previous year.[28] This and other studies are strengthening the evidence base of the disproportionate impact of the pandemic on health-disparate populations.

Excess mortality estimation requires careful development of statistical methods, including selecting an appropriate comparison period, so estimates typically are not available until months after a disaster. In COVID-19, however, these estimates are available on a real-time basis. Media such as the *New York Times*[29] and *The Economist*[30] produced some of the earliest estimates and regularly update the results. The United Kingdom Office for National Statistics has a Web site that allows comparisons of all-cause mortality among European countries,[31] and CDC's weekly COVIDView report includes an analysis of influenza and COVID-19 deaths compared with a seasonal baseline based on previous years.[15]

IMPROVING POPULATION ESTIMATES OF MORTALITY AND MORBIDITY

As with individual counts, population estimation methods require several judgments about definitions, statistical methods, and data collection and use. For instance, increases in cardiac mortality are common following natural disasters,[32] so pandemic-related increases being documented now are plausibly related to stress caused by the pandemic. Whether these excess deaths should be regarded as "caused by" the pandemic is a matter of definitional dispute and an illustration of how population estimation methods require judgments to interpret. In addition, clinically relevant information on prominent comorbidities such as hypertension and diabetes mellitus are sometimes reported, but in some states, especially those such as Louisiana with fragile health systems and large minority subpopulations, those data are only available at the state level, hampering local, community-based interventions.[33]

However, while there is no standard method for generating mortality or morbidity estimates, methodological best practices can be specified. The CDC, the National Institutes of Health, and the National Science Foundation should establish a national research program to advance analytical methods for conducting population-level estimates of mortality and morbidity related to disasters, including the current pandemic. At minimum, urgent guidance is needed on standard comparison periods for excess mortality calculations, the handling of confounding or seasonal structures in the data, and standard sampling frames and survey items for tracking the impacts of the pandemic in each state (recommendation 4-1[4]).

Developing an effective data infrastructure for examining disaster impacts on mortality and morbidity should be a cornerstone of the nation's operational disaster and pandemic response function. Because the analytical sophistication and high-quality fieldwork are generally beyond the capabilities and time availability of most state, local, tribal, and territorial health departments, the responsibility of building and sustaining the capacity of the nation's

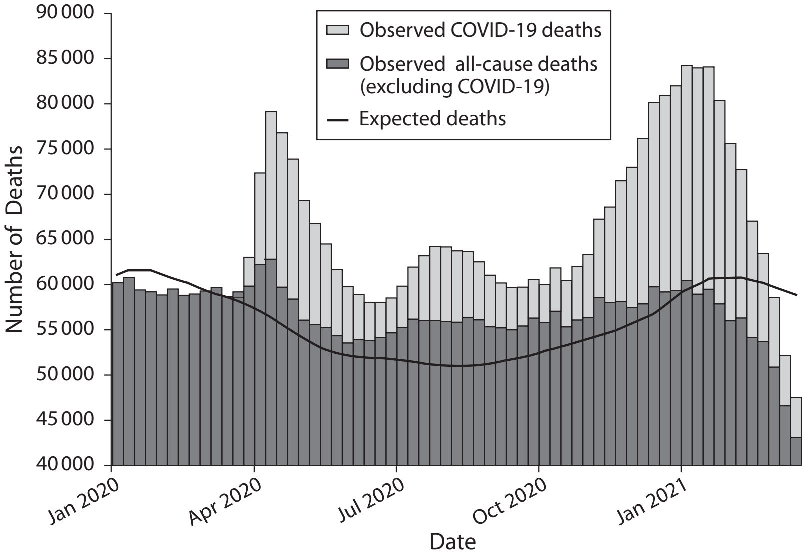

FIGURE 2— Excess Mortality in the United States: January 2020–March 2021

Source. Authors' calculations based on Centers for Disease Control and Prevention data.[26]
Note. The vertical axis starts at 40 000 deaths, and deaths are incompletely reported in February 2021.

existing research and survey infrastructure to support the collection of survey data on the health effects of pandemics rests at the federal level. In particular, the NASEM recommends that the federal statistical system, including the CDC, the Substance Abuse and Mental Health Services Administration, and others, should harness its existing survey infrastructure so that in times of national emergencies they have in place survey instruments that can be immediately used to measure the overall impact of the pandemic from both a health and economic perspective and taking into account the social determinants of health, which will enable time-sensitive positioning of health resources in geographic areas with high health-disparate communities (recommendation 4-2[4]).

BETTER DATA ON COVID-19 DISPARITIES

In this analysis, we have cited multiple examples of the disproportionate burden of COVID-19 cases, COVID-19–related deaths, and other consequences suffered by marginalized populations. To put it starkly, for example, in one of the largest hospitals in New Orleans, Louisiana, 77% of those hospitalized with COVID-19, and 71% of those who died, were Black, although Blacks only represented 31% of this hospital's usual population.[34] At the same time, we documented disparities in access to testing that, if rectified, might identify even greater consequences of COVID-19 in disadvantaged populations.

To accurately determine the toll of the pandemic on health-disparate populations and to inform policies to reduce inequities, risk factors related to the social determinants of health embedded in each of 6 "capitals" must be taken into account: natural environment, built environment, financial, human and cultural, social, and political.[35] For example the natural environment capital includes overcrowded households, which increase the risk of virus transmission,[36] while crowded workplaces (built environment capital) place employees and their family members at risk for infection. Often these employees are predominantly employed as frontline workers who were in the first wave of layoffs (financial capital). Job loss often resulted in stress[37] (social capital), while stigma has been reported (human and cultural capital[38]). The incoherent policies across the federal, state, and local levels pose a critical challenge (political capital). Most prominently, differences in closing and (re)opening of businesses affected those socioeconomically most vulnerable.

Two NASEM recommendations call for an enterprise-wide initiative to strengthen existing death registration systems to improve the quality of pandemic-related mortality data at state, local, tribal, and territorial levels and to improve the quality and utility of morbidity data for surveillance purposes. This requires collaborations among health departments at all levels, as well as the health care system, which will provide an opportunity to incorporate more comprehensive disparities and social determinants of health data from the start and to conduct geospatial analyses. In addition, the NASEM recommendations for improving population estimates of COVID-19 mortality and morbidity lead the way to more complete and comprehensive assessments of the pandemic's consequences for disparate populations. These recommendations also lay the groundwork for the collection of data that can support rigorous research into the role social determinants of health play in the magnitude and severity of the pandemic.

CONCLUSIONS

In a crisis, the public wants to know what is happening and policymakers want reliable data to support evidence-based decision-making. However, the COVID-19 pandemic shows how the availability of different approaches for assessing morbidity and mortality can create confusion. In particular, the availability of different methods generating widely differing estimates creates opportunities for manipulation or the appearance of manipulation. In addition, COVID-19 case data often do not provide meaningful information on the pandemic's disparate impact on disadvantaged populations. Fittingly, to restore trust with the American people, the first element of President Biden's COVID-19 strategy includes an Executive Order on ensuring a data-driven response to COVID-19 and future high-consequence public health threats.[39] Implementing this strategy and addressing the gaps we describe in this article requires an enterprise-wide initiative to strengthen existing death registration systems to improve the quality of pandemic-related mortality data at state, local, tribal, and territorial levels and to improve the quality and utility of morbidity data for surveillance purposes.

Population-based estimates based on sampling or by comparing observed to expected numbers of deaths or cases can complement counts of cases and deaths. While "estimation" sounds less precise than "counting," these methods can provide a more comprehensive assessment of the total impacts of a disaster and provide more detailed information on disparities and social determinants of health. Research is needed, however, to specify methodological best practices and to harness the federal government's existing survey infrastructure so that, in times of national emergencies, survey instruments can be immediately used to measure the overall impact of the pandemic from both a health and socioeconomic perspective. Doing so can minimize increasing the historic burden of disparities and inequities faced by the most vulnerable among us. AJPH

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This research did not involve human participants.

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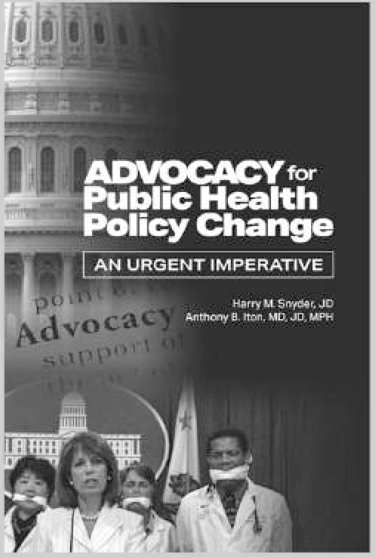

Out-of-Hospital COVID-19 Deaths: Consequences for Quality of Medical Care and Accuracy of Cause of Death Coding

Elizabeth B. Pathak, PhD, Rebecca B. Garcia, MSN, Janelle M. Menard, PhD, and Jason L. Salemi, PhD

Objectives. To examine age and temporal trends in the proportion of COVID-19 deaths occurring out of hospital or in the emergency department and the proportion of all noninjury deaths assigned ill-defined causes in 2020.

Methods. We analyzed newly released (March 2021) provisional COVID-19 death tabulations for the entire United States.

Results. Children (younger than 18 years) were most likely (30.5%) and elders aged 64 to 74 years were least likely (10.4%) to die out of hospital or in the emergency department. In parallel, among all noninjury deaths, younger people had the highest proportions coded to symptoms, signs, and ill-defined conditions, and percentage symptoms, signs, and ill-defined conditions increased from 2019 to 2020 in all age–race/ethnicity groups. The majority of young COVID-19 decedents were racial/ethnic minorities.

Conclusions. The high proportions of all noninjury deaths among children, adolescents, and young adults that were coded to ill-defined causes in 2020 suggest that some COVID-19 deaths were missed because of systemic failures in timely access to medical care for vulnerable young people.

Public Health Implications. Increasing both availability of and access to the best hospital care for young people severely ill with COVID-19 will save lives and improve case fatality rates. (*Am J Public Health*. 2021;111(S2):S101–S106. https://doi.org/10.2105/AJPH.2021.306428)

Deaths from "natural" causes (i.e., noninjury causes) that occur outside the hospital (OH) inpatient setting often represent lost opportunities for life-saving critical care. COVID-19 deaths that occur in the emergency department (ED) should be grouped with OH deaths, not with inpatient deaths as was done in 2 previous studies.[1,2] In the United States, most hospitals are permitted to treat and house patients in the ED for no more than 24 hours. After that time, patients must be either admitted as full inpatients or discharged, typically to home or a long-term care facility. Consequently, noninjury ED deaths are deaths for which critical care (i.e., rescue) was accessed too late.

During a pandemic, all deaths from the pandemic disease should be considered avoidable deaths, even deaths among the very elderly. Nonetheless, in public health it is common to describe deaths among patients who are younger than 65 years as "premature." Premature OH and ED (OH/ED) deaths often are the result of longstanding and systematic barriers in access to high-quality medical care. Although elders aged 65 years and older experience the same barriers to high-quality hospital care as do younger patients, OH/ED deaths in this age group, particularly among those aged 85 years and older, may occur in a planned manner after a known illness and reflect the patient's wishes for end of life care.[2]

During the first pandemic year, COVID-19 fatalities were skewed very sharply toward elders. Nevertheless, there were more than 103 000 "premature" COVID-19 deaths that occurred among persons younger than 65 years in the United

States during 2020. We examined age differences and temporal trends in OH/ED COVID-19 mortality, using death certificate tabulations released on a provisional basis by the National Center for Health Statistics (NCHS).

METHODS

We obtained 3 separate tabulations of deaths involving COVID-19 from NCHS in March 2021, each covering the 2020–2021 pandemic period for the entire United States. The place of death tabulation included all COVID-19 deaths, stratified by age group, month, year, and place of death.[3] The race/ethnicity tabulation included all COVID-19 deaths, stratified by age group and 7 combined categories of Hispanic ethnicity and race.[4] The cause of death tabulation included all deaths, stratified by year, age group, race/ethnicity, and selected underlying causes of death.[5] This file included data for both 2019 and 2020. We used CDC WONDER (Centers for Disease Control and Prevention Wide-ranging ONline Data for Epidemiologic Research) to access data on place of death for all noninjury decedents by age for calendar year 2019.

We analyzed 3 categories of place of death, defined as follows:

- OH/ED deaths included the following places of death listed on the death certificate: ED, dead on arrival, decedent's home, other, and place of death unknown.
- Long-term care and hospice deaths included deaths that occurred in a hospice facility or nursing home or long-term care facility. Note that patients receiving hospice care at home would have place of death listed as decedent's home.
- Hospital inpatient deaths had medical facility–inpatient listed as the place of death.

RESULTS

OH/ED deaths included all decedents who died in a hospital ED, en route to an ED, at home, or at another location outside a health care facility (e.g., workplace). Figure 1 shows the proportion of COVID-19 decedents who died OH/ED through March 2021 by age. Children were most likely to die OH/ED (30.5%), followed by young adults aged 18 to 29 years (28.2%). Elders were least likely to die OH/ED (10.4% to 12.3%).

Temporal trends in OH/ED COVID-19 deaths by age are shown in Figure 2. The highest OH/ED proportions occurred in March 2020, when the pandemic was largely constrained to the greater New York City metropolitan area. After the first month, the age disparity in OH/ED deaths diminished little over time, and in February 2021, COVID-19 decedents aged 0 to 29 years were still 65% more likely to die OH than were older decedents.

Comparison by age of OH/ED mortality for all "natural" causes in 2019 with the COVID-19 results for 2020–2021 revealed several interesting patterns (Figure A, available as a supplement to this article at https://www.ajph.org). First, the association of age with OH/ED mortality was very different in 2019. In contrast to findings for COVID-19, children had the lowest proportion of OH/ED deaths for all noninjury causes. Second, the proportion of children who died OH/ED from COVID-19 in 2020 was much higher than was the proportion of those who died OH/ED from noninjury deaths in 2019 (30.5% vs 19.1%). Finally, among adults, OH/ED death was proportionately more frequent in 2019 than it was in 2020.

Place of death tabulations for COVID-19 decedents stratified by race and ethnicity have not yet been released, so we were unable to directly examine race/ethnicity disparities in OH/ED death. Figure 3 shows that among all COVID-19 decedents, race and

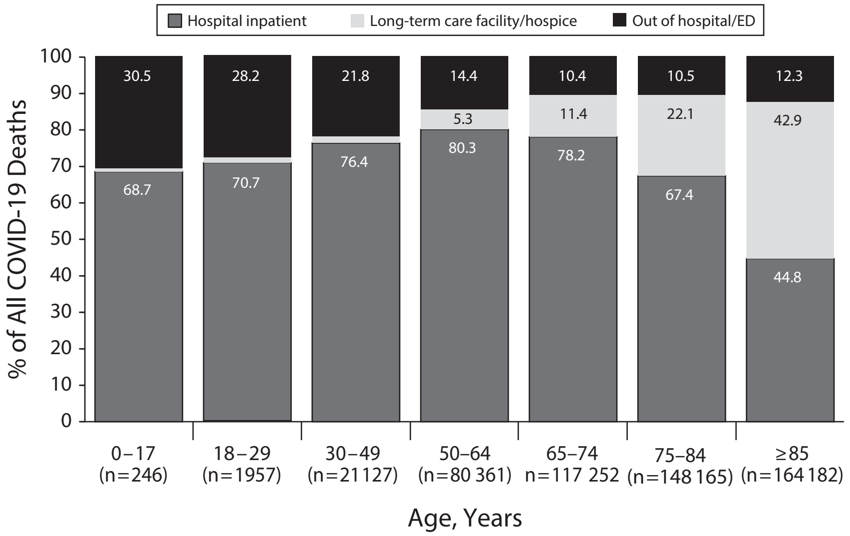

FIGURE 1— Place of COVID-19 Death, by Decedent Age: United States, January 2020–March 2021

Note. ED = emergency department.

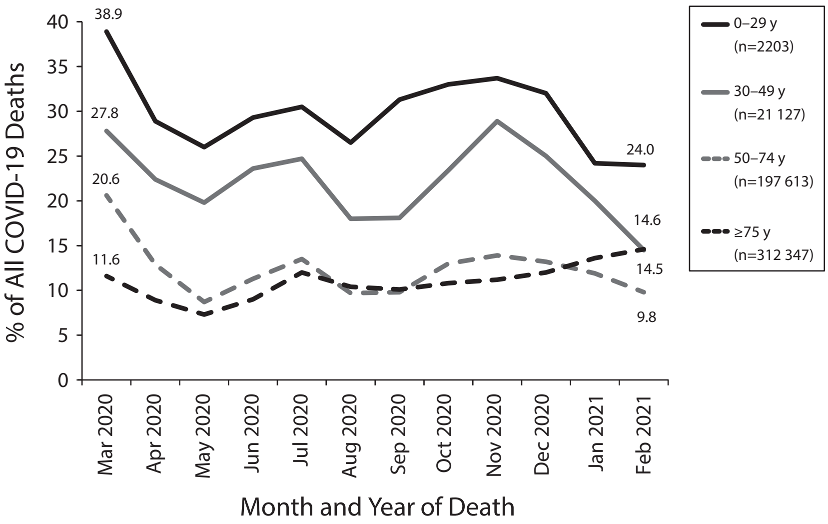

FIGURE 2— **Percentage of COVID-19 Deaths Occurring out of Hospital or in the Emergency Department, by Decedent Age: United States, March 2020–February 2021**

ethnicity varied markedly by age: the majority of child decedents were non-White (39.0% Hispanic, 22.8% Black, 3.7% Asian, 2.0% American Indian/Alaska Native, 1.6% Native Hawaiian/other Pacific Islander, 0.8% more than one race). Similarly, only one quarter (24.6%) of young adult decedents (aged 18–29 years and 30–49 years) were non-Hispanic White. By contrast, the majority of elderly COVID-19 decedents were White.

Symptoms, signs, and ill-defined conditions (SSID) are a group of nonspecific *International Classification of Diseases, 10th Revision* (*ICD-10*; Geneva, Switzerland: World Health Organization; 1992) codes used on death certificates when medical history is absent or is insufficient to confidently ascribe a specific disease as cause of death.[6] SSID is most frequently used for OH/ED deaths. Figure 4 depicts the level of SSID mortality by age and race/ethnicity and the change from 2019 to 2020 in the proportion of all noninjury deaths coded to SSID. Note that the logarithmic scale on the y-axis means that parallel trend lines result when the percentage change from 2019 to 2020 is the same for different groups. Children aged 0 to 14 years had the highest percentage of deaths coded to SSID in 2019, likely because of sudden infant

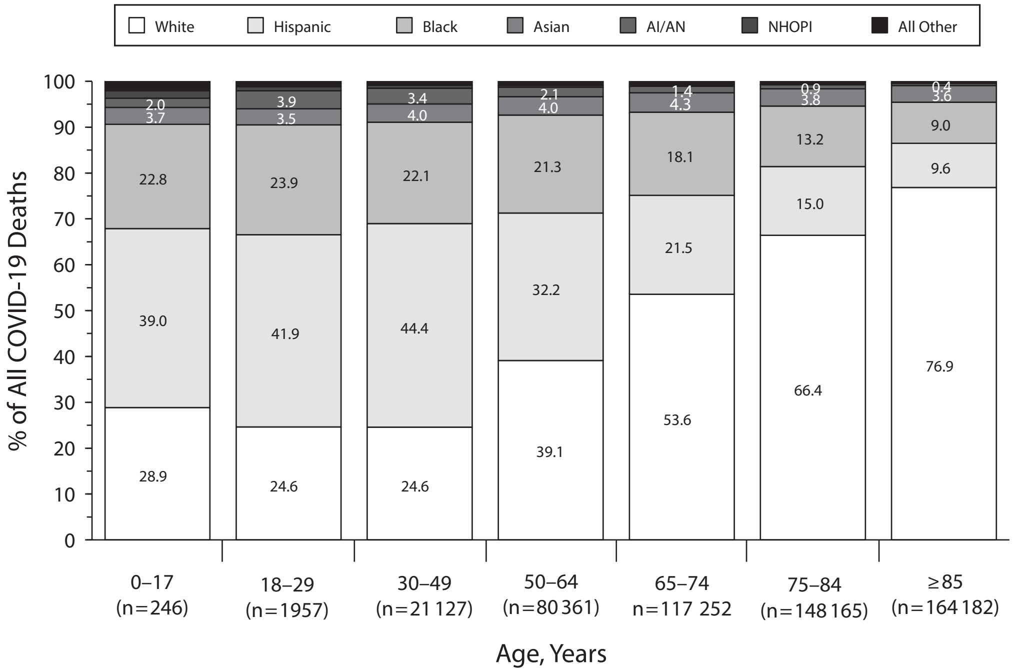

FIGURE 3— **Race and Ethnicity of COVID-19 Decedents, by Age: United States, January 2020–March 2021**

Note. AI/AN = American Indian/Alaska Native; NHOPI = Native Hawaiian or Pacific Islander.

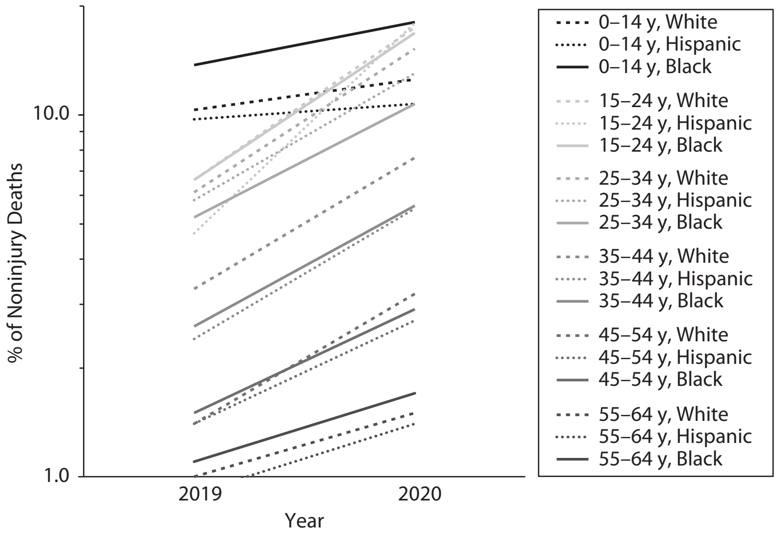

FIGURE 4— **Percentage of All Noninjury Deaths Coded to Symptoms, Signs, and Ill-Defined Conditions, by Age and Race/Ethnicity: United States, 2019 and 2020**

death syndrome, which falls in the SSID *ICD-10* codes. Percentage SSID increased from 2019 to 2020 in children of all racial/ethnic groups, with the strongest increase (from 13.7% to 18.0%) in Black children (Figure 4).

The greatest increase in percentage SSID deaths among all age–race/ethnicity groups was among Hispanic adolescents and young adults aged 15 to 24 years, from 4.7% in 2019 to 17.9% in 2020 (Figure 4). Similarly, percentage SSID in Whites aged 15 to 24 years increased from 6.6% to 17.4% and in Blacks from 6.6% to 16.8%. Among adults of older age groups, percentage SSID increased similarly from 2019 to 2020 for all racial/ethnic groups, but absolute levels declined with age.

DISCUSSION

Taken together, the unlinked provisional data sources we analyzed reveal that child, adolescent, and young adult COVID-19 decedents were much more likely than were older decedents to die OH/ED and overall were predominantly racial and ethnic minorities. Although current data limitations preclude a definitive conclusion that racial and ethnic minorities are more likely than non-Hispanic Whites to die from COVID-19 OH/ED, our results support the need for priority investigation of this hypothesis.

In parallel, the relatively high proportions of all noninjury deaths among children, adolescents, and young adults that were coded to SSID in 2020 suggest that some COVID-19–involved deaths were missed because of systemic failures in timely access to medical care for vulnerable young people.

Premature, OH/ED COVID-19 deaths represent a failure of the medical care system to reach all critically ill patients with life-saving measures.[7] Barriers to accessing high-quality hospital medical care operate at multiple scales[8,9]: the individual person (e.g., lack of health insurance), the household level (e.g., lack of transportation, job and family responsibilities), and the community level (e.g., inadequate or geographically distant hospital facilities). Even in the absence of interpersonal discrimination, structural racism negatively affects non-White patients and families seeking hospital care through multiple mechanisms, including residential segregation.[10,11]

Secondary to the consequences of barriers to quality care, OH/ED deaths also negatively affect the accuracy of cause of death coding on the death certificate.[12] When deaths are unattended or are witnessed only by laypeople, it can be very difficult for physicians to confidently ascribe a specific disease as the underlying cause of death. This is particularly true for decedents who had not received regular health care. SSID cause of death codes are not "garbage" codes, as some investigators have labeled them.[13] They are better thought of as "canary" codes—indications that the health care system has failed to provide adequate medical care at the end of life.[6,14] For example, a 120% increase in the incidence of OH cardiac arrest during the pandemic has been reported,[15] but the prevalence of SARS-CoV-2 infection in those individuals was unknown. One investigation in France found that 22% of those who died at home of cardiac arrest probably or definitely had COVID-19.[16]

Limitations

The very recent death tabulations we analyzed in this study were generated by the NCHS from provisional death certificate files that have not been finalized. Additional deaths may be added for the study period, and individual death records may be modified if additional information becomes available, particularly about causes of death. NCHS has published a full discussion of data limitations online.[17] In addition, the NCHS definition of "COVID-19–involved deaths" includes only deaths for which COVID-19 is listed as an underlying or contributing cause of death. We did not include decedents who were known to have COVID-19 (i.e., had tested positive) but whose death certificate did not mention COVID-19. Currently, there is no centralized and complete data system that would permit the counting of these deaths.

Public Health Implications

Place of death data from the death certificate do not provide any information about the progression of episodes of care (in outpatient, ED, and inpatient settings) in the weeks and days immediately preceding death. Particularly for children, adolescents, and young adults, who have the greatest likelihood of surviving COVID-19 if they receive timely high-quality hospital care, we need further focused research and ongoing surveillance. Several priority research questions emerge from our findings. Had young people who eventually died OH/ER from COVID-19 been previously hospitalized and discharged with a positive prognosis? Had these patients visited an ED previously and been sent home? Are these decedents disproportionately located in geographic areas with fewer acute care hospital beds? To what degree have COVID-19 fatalities been miscoded to SSID?

In the second year of the pandemic, the United States still suffers from inadequate epidemiologic surveillance of COVID-19 incidence, severity, and fatality. The disparate effects of the pandemic on young people, racial and ethnic minorities, rural residents, and other vulnerable groups cannot be adequately understood or effectively ameliorated without rapid improvements in our surveillance systems and improved data transparency and availability. In particular, the timely release to nongovernmental researchers of full death certificate datafiles would broaden the scientific expertise and capacity available to investigate high-priority research questions.

More importantly, the case fatality rate for COVID-19 (regardless of which genetic viral variants are predominant at any given time and place) will always depend on the availability of both accurate medical evaluation and high-quality hospital medical care for severely ill patients. This is true despite the fact that no robust cure for COVID-19 has been identified yet. Multiple organ system pathologies engendered by the virus, still not well understood, often require life-saving rescue in the form of assisted ventilation, temporary renal dialysis, and resuscitation. Increasing both availability of and access to the best hospital care for young people severely ill with COVID-19 will save lives and could possibly reduce racial and ethnic disparities in mortality as well.

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CONTRIBUTORS

E. B. Pathak conducted the analyses, created the figures, and wrote the first draft of the article. R. B. Garcia, J. M. Menard, and J. L. Salemi revised and edited the article. All authors conceptualized and designed the study.

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CONFLICTS OF INTEREST

The authors have no conflicts of interest to report.

HUMAN PARTICIPANT PROTECTION

This study used only publicly available, de-identified data sets and was therefore exempt from institutional review board review.

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Aggression, Escalation, and Other Latent Themes in Legal Intervention Deaths of Non-Hispanic Black and White Men: Results From the 2003–2017 National Violent Death Reporting System

Alina Arseniev-Koehler, MA, Jacob Gates Foster, PhD, Vickie M. Mays, PhD, MSPH, Kai-Wei Chang, PhD, and Susan D. Cochran, PhD, MS

Objectives. To investigate racial/ethnic differences in legal intervention–related deaths using state-of-the-art topic modeling of law enforcement and coroner text summaries drawn from the 2003–2017 US National Violent Death Reporting System (NVDRS).

Methods. Employing advanced topic modeling, we identified 8 topics consistent with dangerousness in death incidents in the NVDRS death narratives written by public health workers (PHWs). Using logistic regression, we then evaluated racial/ethnic differences in PHW-coded variables and narrative topics among 4981 males killed by legal intervention, while adjusting for age, county-level characteristics, and year.

Results. Black, as compared with White, decedents were younger and their deaths were less likely to include PHW-coded mental health or substance use histories, weapon use, or positive toxicology for alcohol or psychoactive drugs, but more likely to include "gangs-as-an-incident-precipitant" coding. Topic modeling revealed less frequent thematic representation of "physical aggression" or "escalation" but more of "gangs or criminal networks" among Black versus White decedents.

Conclusions. While Black males were more likely to be victims of legal intervention deaths, PHW-coded variables in the NVDRS and death narratives suggest lower threat profiles among Black versus similar White decedents. The source of this greater risk remains undetermined. (*Am J Public Health*. 2021;111(S2):S107–S115. https://doi.org/10.2105/AJPH.2021.306312)

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In the United States, Black Americans are disproportionately more likely to die in what are labeled legal intervention–related deaths, such as police shootings.[1] Indeed, legal intervention deaths are estimated to be 2.8 times greater among Blacks than among Whites.[2] These deaths occur under a variety of circumstances, including confrontation with police or other legally acting persons during arrests or while in legal confinement. Legal intervention deaths have become increasingly prevalent over the past 2 decades.[3]

Previous research has sought to identify characteristics of legal intervention decedents and the circumstances surrounding their deaths in the hopes of illuminating the basis of the race disparity. For example, it could be hypothesized that victims who pose a clear threat to legal authorities (such as by being armed or acting unpredictably, perhaps because of mental illness or substance use) might be at increased risk for suffering a legal intervention death. If legal intervention incidents involving Black men include more indicators of threat, such as weapon use, then this could explain the greater risk for death. However, previous work finds that Black legal intervention decedents, compared with similar White or Hispanic decedents, are less likely to be armed, exhibit less evidence of mental health difficulties, and are less likely to have positive toxicology for illicit substances or alcohol at time of death.[2–5] Nevertheless, there may be subtle, but unrecognized, clues in descriptions of lethal legal interventions that could clarify unrecognized risk indicators contributing to the greater likelihood of these deaths of Black men.

In the current study, we applied advanced topic modeling methods to illuminate indicators of threat that may be associated with legal intervention deaths among men varying by race/ethnicity. Employing records from the 2003–2017 National Violent Death Reporting System (NVDRS), we used the written summaries of violent deaths in the NVDRS to inductively identify latent descriptors of threat and dangerousness, such as physical aggression. This possibility has not been studied at scale before, to our knowledge. Our goal was to investigate whether unidentified race-related factors play a role in the excess risk for legal intervention deaths seen among Black men.

METHODS

The NVDRS, compiled by the Centers for Disease Control and Prevention (CDC), provides public health surveillance for violent deaths (e.g., suicide, homicide) in the United States.[1] As of 2017, the NVDRS included information on more than 330 000 deaths forwarded by state public health departments from 34 states and the District of Columbia. The death records themselves are created by trained public health workers (PHWs) who use a common, highly articulated CDC coding manual to assign values to multiple variables (e.g., demographics, factors surrounding the death, toxicology results). PHWs also compose 2 brief, narrative summaries describing the circumstances of the death, one drawn from law enforcement reports and the other from medical examiner or coroner reports. We preprocessed these 2 narratives (to standardize abbreviations and correct misspellings) and combined them. We then applied a phrase detector[6] to transform commonly co-occurring words into single tokens (e.g., “African American” became “African_American”). This resulted in 307 249 death narratives in which the decedent was aged 12 years or older at time of death. Of these, 79 062 were homicides, with the great majority being males (n = 63 263).

We then classified male deaths as to legal intervention status. Following Barber et al.,[7] we categorized deaths as legal intervention–related if at least 1 of the following precoded attributes was present in the record:

1. manner of death coded as “legal intervention,”
2. circumstances of the incident involved a “legal intervention” death,
3. victim–suspect relationship coded as “killed by law enforcement,”
4. in the absence of a coded victim–suspect relationship, homicide committed by law enforcement officer in line of duty or a civilian in self-defense,
5. death received legal intervention *International Classification of Diseases, Tenth Revision* (*ICD-10*; Geneva, Switzerland: World Health Organization; 1992) code (Y35.0–Y35.4, Y35.6, Y35.7, and Y89.0, excluding legal executions), or
6. death occurred while victim was “in custody.”

This categorization identified 5159 deaths. Finally, we excluded 2 deaths in which the victim was a law enforcement officer and 176 deaths in which the narrative text had fewer than 50 words, as these narratives are unlikely to provide informative contributions to the topic modeling. This exclusion resulted in a final study sample of 4981 deaths. Most (n = 4238; 85%) were by firearms. Further description of the NVDRS data system, data quality, and data validation is available elsewhere.[8]

Study Measures

Public health worker–coded death features. Death records included decedent age at time of death, race/ethnicity, and incident year. We recoded race into 3 categories (non-Hispanic Black, non-Hispanic White, and other). In addition, we used several PHW-coded variables that may reflect dangerousness of encounters: whether the death was precipitated by a serious crime, the decedent used a weapon in the incident, the killing was motivated by or involved gang members, and the decedent had a history of alcohol or substance use problems or a history of mental health difficulties. These 5 variables were coded as yes (1) versus no or unknown (0). Finally, in approximately 70% of cases, the death record included toxicology reports. We recoded these for reported versus not reported: blood alcohol level 0.08 or higher and positive result for any psychoactive drug.

Characteristics of the county where the death occurred. We linked 2 aspects of county-level data to the NVDRS-coded county where the incident occurred: county-level violent crime rate (offenses per 100 000 population) and proportion of non-White county residents.[9]

Narrative-based topics reflecting dangerousness of encounters. To identify latent topics in the narratives, we applied a topic modeling approach. Topic modeling is a machine-learning technique for extracting latent themes from large-scale text data and scoring themes to specific documents.[10–13] A full description of our technique, as implemented in the NVDRS narratives, can be found elsewhere.[14] Briefly, we first used word2vec[15] with Continuous-Bag-of-Words,[6] a word-embedding method, to quantitatively represent the meanings of words in the NVDRS narratives based on their co-occurrences. This method identifies vector representations for words by predicting the presence or absence of words from their various contexts in the corpus. Words sharing more similar contexts—and thus sharing more meaning—tend to have more similar word vectors; similarity between 2 vectors is measured using cosine similarity. We set the dimensionality of word vectors to be 200; we selected this dimensionality by using established quality metrics for word embeddings.[15,16] The resulting embedding matrix had 28 222 rows (1 for each unique word in the narratives) and 200 columns (1 for each component of the 200-dimensional word vectors). This matrix can be thought of as a semantic space, which encodes the meaning of the corpus text.

Next, employing the approach of Arora et al.,[12] we applied a sparse dictionary learning algorithm (K-singular value decomposition, or K-SVD)[17] on this matrix to identify latent topics in the semantic space. We then used several established topic modeling quality metrics to find the best configuration of the model, including coherence of the topics[18] and distinctiveness of topics from one another.[19] These quality measures supported selection of a final model with 225 topics. Adopting methods developed by Arora et al.[10,11] and Arseniev-Koehler et al.,[14] we then assigned each death record a score (0 or 1) for whether the latent topic was present or not in the narrative. This conservative approach assigns a score of 1 to narratives with any amount of a topic present. Finally, we confirmed the robustness and validity of the topic model by employing narratives' topic assignments to predict, using a logistic regression classifier, 25 PHW-coded binary death characteristics with 10-fold cross validation (e.g., whether the victim died in an emergency department, a firearm was the primary weapon, and the victim was recently released from any kind of institution). Across the 25 outcomes evaluated, mean classification accuracy was 82.3% (SD = 7.4%) on held-out validation folds.

The face validity of these latent topics can be discerned by examining words loading highest on each topic, as indexed by cosine similarity scores (these are the most representative words for the topic). As might be expected, the 225 topics ranged across the descriptive landscape of violent death, including administrative words, weapons and ammunition, sounds and smells, emotions, syntactic jargon, body parts, drugs, and locations. From these, 2 of the authors (S. D. C. and A. A.-K.) independently identified 8 topics with 100% agreement that, by face validity, address aspects of dangerous encounters (Table 1).

Data Analysis

We analyzed data by using multiple imputation procedures as implemented in R version 4.0.3 (R Foundation for Statistical Computing, Vienna, Austria). Missing data were rare (< 2.0% for any variable) except for toxicology reports, which were analyzed as subsamples. As a first step, we used linear regression to investigate racial/ethnic differences in study covariates: age, incident year, and county-level characteristics (crime rate and proportion of non-White residents). Previous work suggests that younger individuals are at heightened risk of death by police force[20] and, given the changing state composition of the NVDRS, we adjusted for effects attributable to this factor. County-level violent crime rates and proportion of non-White residents were also treated as possible confounders given previous findings[21] that legal intervention deaths and racial disparities in policing are linked to the place where the incident happened, not merely characteristics of the victim or encounter.

Next, we examined potential racial/ethnic variation in the word count of summaries by using a negative binomial regression model, adjusting for incident year to account for any potential changes in NVDRS reporting. Last, we used logistic regression to investigate race/ethnicity differences in selected PHW-coded variables and the 8 narrative topics potentially indexing dangerousness of the lethal encounter while adjusting for age, incident year, and county-level factors. In the analyses of narrative topics, we additionally adjusted for the number of words in each narrative; our descriptive analyses found Black decedents' narratives were often shorter in length, and shorter narratives are less likely to include any particular topic. From these analyses, we report adjusted odds ratios and their 95% confidence intervals. We also report results of regression modeling and the Wald F test. All significance tests were based on the criterion of a *P* value of less than .05.

RESULTS

As shown in Table 2, compared with White decedents, Black decedents were

TABLE 1— Latent Topics Within the 2003–2017 National Violent Death Reporting System Legal Intervention Death Narratives Indicative of Dangerous Encounters: United States

Narrative Topic Label	% (SE) of Narratives With This Topic	Ten Most Representative Terms
Physical aggression	84.5 (0.5)	tackled, lunged_toward, began_attacking, advanced_toward, attacked, slapped, intervened, shoved, lunged, pepper_sprayed
Fight beginnings	87.8 (0.5)	fight_ensued, gunfire_erupted, physical_altercation_ensued, another_individual, pistol_whipped, gunman, struggle_ensued, scuffle_ensued, suspect, intruders
Justification	24.4 (0.6)	ruled_justifiable, remains_unsolved, 558, gang_motivated, pedestrian_vs_train, road_rage, random_violence, justifiable_self_defense, 3289, considered_justifiable
Escalation	8.3 (0.4)	becoming_increasingly, becoming_more, become_more, increasingly, noticeably, notably, become_increasingly, profoundly, grown_increasingly, generally
Physical posture	41.5 (0.7)	crouching, silhouette, kneeling, northeast, crouched, walkway, platform, stagger, laying, leaning
Causal language	12.3 (0.5)	sparked, preceded, triggered, precipitated, led, prompted, culminated, may_have_contributed, occurred, completely_unexpected
Gangs or criminal networks	45.8 (0.7)	gang, rival_gang, bloods, crips, gang_activity, drug_trade, crips_gang, rival, rival_gang_members, revenge
Hostile confrontation	39.2 (0.7)	home_invasion_robbery, card_game, drug_transaction, gunfight, shootout, scuffle, hostage_situation, verbal_exchange, confrontation, brawl

Note. The sample size was $n = 4981$. “Most representative terms” are the 10 terms with highest cosine similarity to the relevant topic.

far younger ($b = -9.30$; $P < .001$) as were decedents of other races/ethnicities ($b = -6.89$; $P < .001$). More than 69% of all Black men dying by legal intervention were younger than 35 years, and 25% were younger than 22 years. By contrast, just 38% of White men were younger than 35 years with 6% younger than 22 years. Timing of the deaths varied in the NVDRS; Black decedents tended to have an earlier incident year in the database ($b = -0.27$; $P < .05$) as compared with Whites, while decedents of other races/ethnicities tended to have a more recent incident year ($b = 0.51$; $P < .01$). We also observed racial/ethnic differences in the county characteristics where the lethal event occurred: compared with Whites, Black decedents tended to die in counties with higher rates of violent crime ($b = 249.02$; $P < .001$) and higher percentages of non-White residents ($b = 19.07$; $P < .001$), as did decedents of other races/ethnicities ($b = 115.78$; $P < .001$ and $b = 7.26$; $P < .001$, respectively). Narratives describing events for Black decedents included fewer words (adjusted $b = -0.28$; $P < .001$) than those for White decedents, while narratives for decedents of other races/ethnicities included more words (adjusted $b = 0.10$; $P < .001$), after we controlled for year when the death occurred.

Legal intervention deaths often occurred in the context of the commission of a serious crime where weapons were used during the encounter (Table 2). Many decedents were also potentially impaired by consumption of alcohol or other psychoactive substances or had histories of mental health or substance use problems. However, compared with death records of White decedents, Black decedents’ records less frequently included positive histories of mental health or substance use problems or use of a weapon by the decedent during the incident (Table 3), after we adjusted for covariates. Furthermore, in the subsamples of deaths in which toxicology results were available, Black decedents were less likely than Whites to be intoxicated or to screen positive for psychoactive drugs at the time of death, after we adjusted for covariates.

Narrative summaries of these deaths revealed subtle but critical Black–White differences in how these legal intervention deaths were described by the PHW. Compared with incidents involving White decedents, Black decedents’ incidents were less likely to include topics describing physically aggressive actions or indicators of escalation, but more likely to include language related to characterizations of gangs or criminal networks. Finally, compared with White decedents, narratives for decedents of

TABLE 2— Characteristics of Legal Intervention–Related Deaths Among Males, Aged 12 Years and Older, by Racial/Ethnic Background: United States, National Violent Death Reporting System, 2003–2017

Characteristics	Non-Hispanic Black, No. or % (SE)	Non-Hispanic White, No. or % (SE)	Other, No. or % (SE)
No. of deaths	1752	2317	912
County of incident			
County violent crime offenses, no. per 100 000 population***	589.4 (7.9)	340.4 (4.7)	456.2 (7.4)
County non-White population, %**	40.3 (0.4)	21.2 (0.3)	28.5 (0.5)
Victim age in years, mean***	31.3 (0.3)	40.6 (0.3)	33.7 (0.4)
Proximal factors, %			
Positive history alcohol or substance use problems***	7.1 (0.6)	23.9 (0.9)	25.5 (1.4)
Positive history of mental health problems***	6.2 (0.6)	17.8 (0.8)	11.1 (1.0)
Death precipitated by a serious crime*	73.7 (1.1)	74.6 (0.9)	78.2 (1.4)
Victim used a weapon***	52.7 (1.2)	62.4 (1.0)	61.4 (1.6)
Death was motivated by or involved gangs***	3.5 (0.4)	0.9 (0.2)	4.1 (0.7)
Narrative topics for dangerous encounters present, %			
Physical aggression***	78.5 (1.0)	88.0 (0.7)	87.1 (1.1)
Fight beginnings*	87.4 (0.8)	87.0 (0.7)	90.5 (1.0)
Justification	25.4 (1.0)	24.4 (0.9)	22.7 (1.4)
Escalation***	5.0 (0.5)	10.5 (0.6)	9.0 (0.9)
Physical posture, %***	38.0 (1.2)	43.7 (1.0)	42.6 (1.6)
Causal language**	11.7 (0.8)	13.7 (0.7)	10.0 (1.0)
Gangs or criminal networks***	46.8 (1.2)	42.5 (1.0)	52.2 (1.7)
Hostile confrontation***	32.8 (1.1)	41.5 (1.0)	45.3 (1.6)
Characteristic of narrative: narrative word count, mean***	203.9 (3.7)	267.0 (4.5)	310.5 (9.8)
Subsamples of deaths that included toxicology reports			
Blood alcohol level			
No. of deaths tested for alcohol levels	1117	1656	724
Blood alcohol level > 0.8, %***	21.5 (1.0)	35.5 (1.0)	28.5 (1.5)
Presence of psychoactive drugs			
No. of deaths screened for psychoactive drug toxicology	1225	1716	758
Positive for psychoactive drugs, %***	48.7 (1.2)	58.6 (1.0)	61.8 (1.6)

Note. The sample size was 4981. For death records that included toxicology reports, n = 3497 for blood alcohol level and n = 3699 for toxicology screen for psychoactive drugs.

*$P < .05$; **$P < .01$; ***$P < .001$.

other races/ethnicities were also more likely to include the gangs or criminal networks topic.

DISCUSSION

Legal intervention deaths are a relatively rare occurrence among the nation's total homicides.[2,3,7] They are, however, among some of the most highly contested homicides. Investigations of these deaths have revealed that approximately a fifth likely involve mental health crises or substance use problems,[22] which may lead to confrontational behavior with law enforcement (so-called "suicide by cop"). Many others occur in the context of serious, felonious crime. Legal intervention deaths are also marked by important risk patterns wherein Black men, and young Black men especially, are at much greater risk in their interactions with law enforcement than are White

TABLE 3— Partial Results of Logistic Regression Models Estimating Proximal Factors and Narrative Topics Associated With Legal Intervention Deaths Among Males, Age 12 Years and Older, by Race/Ethnicity: United States, National Violent Death Reporting System, 2003–2017

	Race/Ethnicity[a]	
Characteristics	**Non-Hispanic Black, No. or AOR (95% CI)**	**Other, No. or AOR (95% CI)**
Total sample	1752	912
Proximal factors		
Positive history alcohol or substance use problems	0.29 (0.28, 0.37)	1.09 (0.90, 1.33)
Positive history of mental health problems	0.38 (0.30, 0.50)	0.60 (0.47, 0.77)
Death precipitated by a serious crime	0.86 (0.72, 1.01)	1.10 (0.91, 1.33)
Victim used a weapon	0.64 (0.55, 0.74)	0.93 (0.80, 1.11)
Death was motivated by or involved gangs	4.07 (2.32, 7.15)	4.23 (2.40, 7.45)
Narrative topics for dangerous encounters present		
Physical aggression	0.65 (0.52, 0.81)	0.87 (0.67, 1.13)
Fight beginnings	1.11 (0.89, 1.40)	1.20 (0.91, 1.57)
Justification	1.07 (0.90, 1.28)	0.76 (0.63, 0.93)
Escalation	0.73 (0.54, 0.99)	0.78 (0.58, 1.05)
Physical posture	1.01 (0.86, 1.19)	0.79 (0.66, 0.94)
Causal language	1.16 (0.92, 1.45)	0.63 (0.48, 0.82)
Gangs or criminal networks	1.34 (1.14, 1.56)	1.26 (1.07, 1.50)
Hostile confrontation	0.91 (0.78, 1.07)	1.14 (0.97, 1.35)
Subsamples of deaths that included toxicology reports		
Blood alcohol level		
No. of deaths tested for blood alcohol levels	1117	724
Blood alcohol level > 0.8	0.55 (0.45, 0.67)	0.77 (0.63, 0.94)
Presence of psychoactive drugs		
No. of deaths screened for psychoactive drug toxicology	1225	758
Positive for psychoactive drugs	0.60 (0.50, 0.81)	0.93 (0.77, 1.12)

Note. AOR = adjusted odds ratio; CI = confidence interval. The sample size was n = 4981, including 2317 non-Hispanic Whites. For toxicology screening variables, the sample size was n = 3497 (including 1656 Whites) for blood alcohol levels and 3699 (including 1716 Whites) for psychoactive drug toxicology reports. Effects tested by adjusting for decedent's age, characteristics of the county where the incident occurred, year of the incident, and, for narrative topics only, narrative word count.

[a] Referent = non-Hispanic White.

men.[2] Importantly, some of these risk patterns may represent public health opportunities to reduce mortality, particularly among young Black men.

The NVDRS represents an important official source for much of what is known about violent death in the United States, including legal intervention deaths.[1,23] Using variables coded into the NVDRS (e.g., sex, *ICD* code, type of weapon, toxicology report), previous studies have shown that Black men who die by legal intervention appear to pose lower immediate threat to law enforcement as compared with White men who also die by legal intervention.[24] In addition, their deaths are less consistent with possible "suicide by cop" motivations,[2,24] as Black legal intervention decedents are less likely than similar Whites to have histories of mental health problems or substance abuse, or evidence of current drug or alcohol consumption at time of death.[24]

Our study extends these findings by making use of a large, mostly untapped source of information on the legal intervention deaths within the NVDRS death narratives. Traditional qualitative methods are impractical for analyzing the hundreds of thousands of NVDRS narratives, though previously some have mined small portions of them. For example, researchers have used simple text searches[25,26] and case sampling employing combinations of precoded variables(s)[22,24,27,28] to isolate samples of death narratives that are then subjected to traditional qualitative methods. This work has successfully isolated the importance of bullying in sexual minority youth suicides,[25] characteristics of gang-related killings,[28] and the variables that we used to identify legal intervention deaths in the NVDRS.[7] But much of the potential value of the narratives has remained out of reach.

To that end, we applied a novel machine-learning approach to unlock the thematic information contained within the narratives. Focusing on themes relevant to aggression, threat, and danger posed by the incident, we found that nuanced themes of danger are described in these narratives, such as specific physically aggressive actions (e.g., "lunged toward"). We also observed a pattern of racial/ethnic differences in the frequency of these themes among legal intervention deaths. For example, incidents involving Black male decedents, as compared with similar Whites, were less likely to involve descriptions of physically aggressive actions or escalation (e.g., "becoming increasingly") but more likely to include descriptions of gangs and criminal networks. By using topic modeling, we were able to both confirm and extend characterization of race differences associated with descriptions of legal intervention deaths.

At a more general level, our topic modeling methodology also offers 2 potential benefits when applied to administrative data such as the NVDRS. First, it may prove a useful approach to inductively identify characteristics of death incidents mentioned in the NVDRS narratives, but not as yet included in its precoded variables. Second, it offers a way to validate PHW coding of variables. For example, although gang-motivated or -involved factors, as indexed by the PHW-coded variable, were rarely present in legal intervention deaths, topic modeling revealed that this characterization was quite common in the death narratives. Elsewhere,[28] NVDRS underreporting of gang involvement, especially among deaths involving non-Hispanic Whites and American Indian/Alaska Natives, has already received note. Other topics picked up by our model but not examined in this study (e.g., topics about mental health) might also be useful to extend or triangulate other PHW-coded variables.

Limitations

Our study has several limitations to be considered. First, while we investigated characteristics of the incident, victim, and county where the incident occurred, we did not directly account for the local racial climate, something that has been suggested as playing a role in the racial disparities observed in legal intervention deaths.[29] In some neighborhoods, Black men may be more likely to be stopped by police in the first place, and Blacks are more likely than Whites to be subject to use of force by law enforcement.[2] Second, the NVDRS is a relatively new administrative database that has been shown to include a fairly comprehensive count of fatal police shootings[30] and legal intervention deaths,[7] but only within the limited set of states that it covers. The recent expansion of the NVDRS to include all 50 states will enable more detailed future work on geographic variation.

Third, the NVDRS is a set of abstracted records compiled by multiple state-based PHWs. Although coders undergo extensive training and use a detailed, standardized codebook, and the abstracted information undergoes numerous, ongoing data validation checks, PHWs may still vary somewhat in their reporting. Also, the database summarizes existing death records but does not investigate original circumstances. Hence, data quality may vary in indeterminate ways at multiple levels (the death is underinvestigated, the report is inaccurately or underreported, or the PHW errs in completing the NVDRS record). All of these factors may introduce biases. Finally, our topic modeling approach, though ideal for processing large databases and avoiding limitations of the need for a priori text search terms, uses alternate validity checks rather than traditional text search strategies[25,30] where all identified cases are closely read for accuracy by human analysts. Metrics reported here support the validity of our approach, but some records remain inaccurately classified. The likely direction of bias is toward the null.

Despite these limitations, results presented here provide further evidence for the role of racially infused perceptions of threat in incidents of legal intervention and police shooting deaths.[2] In both the PHW-coded variables and the topics identified via a novel topic modeling approach, our results suggest that circumstances involving Black decedents from legal interventions include fewer indicators of threat when compared with similar White male decedents. These findings hint at differential, race-related threat thresholds for lethal legal intervention. Elsewhere,[31] research indicates that there is a greater propensity to associate perceptions of threat and criminality with Black men where, for example, young Black men's size and muscularity tend to be overestimated. Furthermore, the overestimation occurs more often with Black men than with White men. This propensity appears to lead to overestimation of danger in situations in which law enforcement is required to interpret ambiguous behavior and circumstances.[32] As a consequence, evidence reported elsewhere suggests that Black individuals are more likely than Whites to be erroneously perceived as holding weapons, when they are in fact holding benign objects.[33] Simulation studies also find that the decision to shoot occurs faster when the target is Black versus White.[29]

Finally, while our core interest lay in characterizing narrative descriptions of the danger or threat posed by the incident, we unexpectedly observed that legal intervention narratives tended to be systematically shorter for Black versus White men. Whether this reflects the amount of information gathered in original law enforcement, coroner, and medical examiner reports or the level of detail retained by PHWs is indeterminable. Regardless of the origin for difference in length, the NVDRS is an official source of information for ascertaining circumstances of death, and shorter narratives provide less information for investigations.

Public Health Implications

Substantively, this work builds on a growing body of scholarship seeking to understand racial disparities in legal intervention deaths, especially police shootings. Using written summaries from public health workers in the 2003–2017 NVDRS, the current study offers new evidence that incidents involving Black decedents who die by legal intervention are described differently than those involving White men. As predicted, the narratives suggest that Black legal intervention deaths, as compared with Whites, are associated with characteristics that pose lower objective threat profiles for law enforcement. At the same time, there is also evidence that these deaths are less fully described for reasons that are unknowable at this point. By applying a state-of-the-art topic modeling technique to a public health administrative database, we were also able to demonstrate the utility and efficiency of this approach, offering a pathway for greater exploration of racial inequities using this important federal data system. Future public health efforts to reduce racial differences in perceived threat or harm in police interactions with young Black males are clearly warranted.

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CONFLICTS OF INTEREST

The authors have no conflicts to disclose.

HUMAN PARTICIPANT PROTECTION

This study was ruled exempt from human participant review by the UCLA institutional review board because it used secondary, de-identified data.

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Ascertainment of Patient Suicides by Veterans Affairs Facilities and Associations With Veteran, Clinical, and Suicide Characteristics

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Objectives. To evaluate the sensitivity of health care facility documentation of suicide deaths among US veterans with recent Veterans Health Administration (VHA) care and assess variation in identification by veteran, clinical, and suicide death characteristics.

Methods. Cross-sectional analyses included 11 148 veterans who died by suicide in 2013 to 2017, per National Death Index death certificate information, with VHA encounters in the year of death or the previous year. Facility suicide ascertainment was assessed per site reports in the VHA Suicide Prevention Applications Network. Bivariate and multivariable analyses assessed ascertainment by decedent demographic, clinical, utilization, and method of suicide characteristics.

Results. Site reports identified 3667 suicide decedents (32.9%). Veteran suicide decedents identified by facilities were more likely to be younger and with clinical risk factors and more recent VHA encounters. Suicide deaths involving poisoning were less likely to be identified than deaths involving other methods.

Conclusions. VHA facility ascertainment of suicide deaths among recent patients was neither comprehensive nor representative. Findings will inform efforts to enhance facility suicide surveillance and veteran suicide prevention. (*Am J Public Health*. 2021;111(S2):S116–S125. https://doi.org/10.2105/AJPH.2021.306262)

Suicide is the 10th leading cause of death in the United States,[1] and the Department of Veterans Affairs (VA) has identified suicide prevention as its top clinical priority.[2] In 2017, the suicide rate among veterans was 50% greater than the rate among nonveteran adults.[3] Among veterans, the age-adjusted suicide rate was 18% higher among those seeking care in the VA health system—the Veterans Health Administration (VHA)—than among other veterans.[3] VHA is the largest integrated health care system in the United States and provides care to more than 6 million veterans each year at more than 1200 locations.[2] To support veteran suicide prevention, VA has adopted a public health approach to suicide prevention that emphasizes enhanced risk identification, timely access, crisis supports, and ongoing surveillance.[3–5]

Health care providers have a responsibility to assess and recognize suicide risk in their patients,[6] and health systems have enhanced tools to support risk assessment.[7–10] Suicide surveillance, a key element of suicide prevention strategies,[2,11–13] is consistent with the population health focus of managed health systems,[14] which involves tracking patient well-being and adverse events that commonly occur in community settings. It is understood that clinician assessments of suicide risk may be affected by patient and clinician characteristics[15]; however, little is known regarding health system ascertainment of suicide mortality in their patient populations,[16] nor how this may be affected by patient, clinical, or suicide event characteristics.

Suicide surveillance faces challenges that may affect health care facility ascertainment of patient suicide deaths. These include cause-of-death misclassification[17] and underreporting.[18] Accurate classification of intent to die may vary

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depending on method of suicide[18]; for example, deaths involving hanging or firearms may be more easily identified as suicides than those involving poisoning and drowning.[19,20] Suicide identification may also differ in association with decedent sociodemographic characteristics, including age, sex, and race/ethnicity. Potential causes include differential method of suicide and completion of autopsies.[19,21] Stigma surrounding suicide could further affect accurate suicide ascertainment and reporting.[19,22]

Suicide and other mortality surveillance systems also face challenges related to lagged availability of comprehensive mortality data.[11,23] The gold standard of US mortality databases is the Centers for Disease Control and Prevention (CDC) National Death Index (NDI),[24] which compiles death certificate data from state vital statistics offices. NDI mortality data for a given calendar year can take an additional year to become available, and search and processing steps require additional time. Death certificate data for injury-related deaths such as suicide also take longer to become available than for other deaths.[25] Some communities and health systems have developed alternative approaches for more real-time mortality surveillance.[16,26] In addition to comprehensive annual NDI searches,[27] in 2008, VA established an infrastructure for facility-level veteran suicide reporting,[28] which makes data available for internal use months or years before nationwide death certificate information is available.

VHA facility-level suicide surveillance is led by suicide prevention coordinators (SPCs) based at VHA medical centers and very large community-based outpatient clinics. Responsibilities of SPCs include maintaining records of suicide deaths among VHA patients and other veterans in the community.[29] Veteran suicide deaths are brought to the attention of SPCs by other veterans, family members of decedents, or established collaborations with local coroners and medical examiner offices.[30] From 2008 to mid-2019, SPCs and associated suicide prevention staff entered records of suicide-related events into a VHA system known as the Suicide Prevention Applications Network (SPAN).[28,29] Event records can be entered in SPAN at any time, and information is available to users upon entry, making site reports a timely and convenient alternative to the gold standard NDI mortality data. Information collected through SPAN are used for reports to local VHA leadership, root-cause analyses,[23] and behavioral health autopsy reports.[30] Assessments of SPAN reports regarding nonfatal suicide attempts and completion of root cause analyses regarding suicide deaths shortly following inpatient discharges indicate that VHA facility documentation of suicide-related events is incomplete.[23,29] To date, however, little is known regarding the overall sensitivity of facility documentation of veteran suicide deaths.

Since 2007, VHA has conducted national veteran suicide surveillance using NDI search results.[4,27] In 2012, VA established, in partnership with the Department of Defense, a joint Mortality Data Repository (MDR), which includes death certificate data from annual NDI searches inclusive of the all-veteran population. While comprehensive, MDR updates depend on the timing of annual NDI updates, and data commonly become available 1 to 2 years following completion of a given year. The MDR is a key component of national veteran suicide surveillance, supporting annual national VA reports regarding veteran suicide[3] and reporting specific to veterans with recent VHA care. MDR data can also be used to evaluate facility identification of suicide deaths.

To support ongoing VA suicide prevention efforts, we examined the sensitivity and representativeness of local VHA facility suicide death ascertainment, using MDR-indicated suicide deaths as the gold standard, as well as how site ascertainment of suicides may be affected by patient characteristics, health system engagement, diagnoses associated with suicide risk, and method of suicide death. For example, we hypothesized that local VA suicide surveillance would under-capture veteran VHA user suicide deaths and would document a greater proportion of suicide deaths among suicide decedents who were younger, whose suicide death involved suffocation or firearms, and who had mental health–related and more recent VHA encounters before death, as compared with other veteran VHA user suicide decedents.

METHODS

Using MDR records, we identified recent veteran VHA users who died from suicide, and we assessed whether these suicide deaths were identified in VHA facility suicide death reports, per SPAN.

Study Population

The study population was composed of all recent veteran VHA users who died by suicide in 2013 to 2017 in the 50 US states or the District of Columbia (n = 11 148). Study members must have had at least 1 VHA inpatient or outpatient encounter in the year of their death or year before (“recent users”). Mortality information for the underlying cohort of decedents was drawn from the MDR, which contains death certificate data obtained from annual NDI searches. Suicide as cause of death was categorized using *International Statistical Classification of Diseases and Related Health Problems, Tenth Revision* (*ICD-10*; Geneva, Switzerland: World Health Organization; 2011) codes as follows: X60–X84, Y87.0, and U03.

Measures

The outcome of interest was facility documentation of the veteran's suicide death, as indicated per SPAN records. We identified SPAN indication of suicide mortality by records with a Self-Directed Violence Classification of "suicide" and outcome indicated as "death." We matched records in SPAN and the MDR based on Social Security Number. Matching criteria required the SPAN record's date of suicide death to be within 3 months of the MDR death certificate–indicated date of death.

We identified patient-level demographic, clinical, and health care utilization measures that could be associated with local suicide death ascertainment. We derived measures from the VHA National Patient Care Database, Corporate Data Warehouse, and Planning Systems Support Group Geocoded Enrollee Files. Demographic variables included sex, age (categorized as 18–34, 35–54, 55–74, or 75–115 years), race/ethnicity (White, Black, Hispanic, other, or unknown), marital status (married or unmarried), rurality of home address (urban or rural), and region of the country (Northeast, Midwest, South, or West, per US Census designations by state). We also examined characteristics of death, namely year of death and method of suicide, per MDR death certificate information. We categorized method of suicide using *ICD-10* codes as follows: firearms (X72–X74), poisoning (X60–X69), suffocation (X70), and other (X71, X75–X84, Y87.0, U03).

We examined clinical characteristics of decedents in the 12 months before death. These included an overall measure of any mental health or substance use disorder (SUD) diagnosis, individual diagnostic categories for any SUD, anxiety, bipolar disorder, depression, posttraumatic stress disorder (PTSD), or schizophrenia,[3] as well as indications of homelessness, per *International Classification of Diseases, Ninth Revision, Clinical Modification* (Hyattsville, MD: National Center for Health Statistics; 1980) and *International Classification of Diseases, Tenth Revision, Clinical Modification* (Hyattsville, MD: National Center for Health Statistics; 2000) diagnosis codes (Table A, available as a supplement to the online version of this article at http://www.ajph.org). We considered at least 1 diagnosis code from a VHA encounter a positive indication. We assessed any documentation of a nonfatal suicide attempt per VHA encounter *ICD* diagnosis codes or event records in SPAN, as well as history of a clinical high risk for suicide flag and documentation of a suicide safety plan. We assessed the following attributes of VHA health care use before death: facility type (VHA medical center, community-based outpatient clinic, or other) and setting (inpatient mental health, inpatient non–mental health, emergency department, outpatient mental health, or outpatient non–mental health) of most recent VHA encounter. We also assessed completed screens for PTSD, depression, and alcohol use disorder in the 12 months before death and any missed VHA appointments in the 1 month before death.

Statistical Analyses

Univariate analyses examined characteristics of recent veteran VHA user suicide decedents in 2013 to 2017. Bivariate analyses assessed differences among suicide decedents by whether their suicide death was identified by facilities and documented in SPAN. We calculated effect size for each level of a covariate by using relative risk for categorical variables and Cohen's d for continuous variables. We considered relative risk less than 0.5 or greater than 2.0 clinically significant, and we assessed small, medium, and large effects for Cohen's d as 0.2, 0.5, and 0.8, respectively. We assessed statistical significance for differences between facility-identified decedents and nonidentified decedents by using the χ^2 test for categorical variables and *t* test or Wilcoxon rank sum test for continuous variables. Finally, to assess the association between suicide decedent characteristics and ascertainment, we used a multivariable logistic regression model with random intercepts for VHA administrative parent facilities (n = 140; these designate VHA sites managed by a common administrative leadership team) to model the adjusted odds of facility suicide death identification that were associated with patient sociodemographic and clinical characteristics and method of suicide death, adjusting for other characteristics. We conducted analyses with SAS version 9.4 and SAS Enterprise Guide 8.2 (SAS Institute Inc, Cary, NC).

RESULTS

We identified 11 148 recent veteran VHA users who died by suicide between January 1, 2013, and December 31, 2017, per death certificate information in the MDR. Of those, we found suicide death records for 3667 decedents (32.9%) to have been documented by facilities in SPAN.

Table 1 presents univariate and bivariate descriptive statistics regarding recent veteran VHA user suicide decedents, overall and by facility identification. Veterans who died by suicide in 2013 to 2017 had an average age of 60.1 years and were primarily male (95.9%), White (80.8%), and residing in urban areas (64.2%). In the 12 months before death, 55.4% had a VHA-documented mental health or SUD diagnosis, 4.2% had a documented nonfatal suicide attempt, and 5.6% received a clinical flag for high suicide risk.

Bivariate analyses indicated that demographic, geographic, clinical, and mortality characteristics of recent veteran VHA user suicide decedents were associated with likelihood of the decedent's suicide death having been recorded by facilities. VHA facilities identified 41.9% of suicide deaths among recent veteran VHA users who were female and 32.5% among those who were male. Decedents identified by sites were younger than those who were not identified (mean age 53.6 vs 63.3 years). Among suicide decedents aged 18 to 34 years, sites identified suicide deaths of 52.1%. Among those aged 75 years or older, sites identified 17.5%. Decedents whose race/ethnicity was categorized as "other"—inclusive of Asian/Pacific Islander, American Indian/Native Alaskan, and multiple races—were more likely to be identified (45.7%) than other race/ethnicity groups (e.g., 31.7% among White decedents).

Site identification of suicide deaths was greatest among users in the West (39.4%) and lowest in the South (27.2%). Facility-identified suicide decedents resided nearer to VA facilities (average distance 12.5 miles; SD = 21.9) than nonidentified suicide decedents (13.0 miles; SD = 19.7), and identification was greater for decedents living in urban areas (34.2%) compared with those in rural areas (31.5%).

Time since most recent VHA encounter was briefer among facility-identified suicide decedents (average 48.6 days; SD = 86.5) than among nonidentified suicide decedents (103.5 days; SD = 129.0). Patients whose last VHA encounter occurred in inpatient settings and those whose last use occurred in an outpatient mental health setting were more likely be identified as suicide decedents by facilities, compared with those seen in other settings. Facility-identified suicide decedents had received more VHA outpatient visit days (average 25.4 [SD = 28.0] vs 13.4 [SD = 19.3]) and more inpatient stays (average 0.55 [SD = 1.33] vs 0.24 [SD = 0.83]) in the 12 months before death.

We found significant crude associations between facility identification and each mental health and SUD diagnostic category examined. Veterans with any mental health or SUD diagnosis in the 12 months before death were 2.6 times as likely as those without a mental health or SUD diagnosis to have their death documented by facilities. Relative risks for facility identification associated with having a diagnosis of depression or PTSD were each 2.0. Having previous nonfatal suicide attempts documented per diagnosis codes or SPAN reports, presence of a clinical high risk for suicide flag, documentation of a suicide safety plan, and other indicators of VHA use were also associated with elevated likelihood of facility identification.

Overall site documentation of suicide deaths among recent veteran VHA users increased slightly over the 5-year period of interest, from 29.3% capture in 2013 to 33.3% in 2017. Likelihood of facility identification differed by a decedent's method of suicide. Decedents who died by suffocation were most likely to have had their death documented by facilities (44.5%), and those who died by poisoning were captured least frequently (26.7%).

In multivariable logistic regression with random facility effects, few patient characteristics remained significantly associated with facility identification of a recent veteran VHA user's suicide death when we adjusted for all covariates (Table 2). The facility average odds of SPC identification were lower for older suicide decedents than younger decedents, and patients with a more recent VHA encounter before death had greater odds of identification than those for whom more time had passed since their most recent encounter, with adjustment for covariates. Veterans whose last VHA visit was in an inpatient non–mental health setting or outpatient mental health setting had increased odds of being identified by facilities, as did those with a recent diagnosis of depression or PTSD. In the adjusted model, number of outpatient visit days, having a recent clinical flag for high risk of suicide, and suicide death involving suffocation were each associated with greater odds of facility identification. Number of inpatient discharges per patient was inversely associated with adjusted odds of facility identification. Suicide involving poisoning was associated with lower odds of identification than suicide involving other methods.

DISCUSSION

VHA facilities identified suicide deaths among 33% of recent veteran VHA users who died by suicide in 2013 to

TABLE 1— Characteristics of Recent Veteran VHA Patient Suicide Decedents by Facility Identification of Suicide: United States, 2013–2017

		Suicide Identified by Facility		Effect Size		
	All, No. (Column %) or Mean ± SD	Yes, No. (Row %) or Mean ± SD	No, No. (Row %) or Mean ± SD	RR	Cohen's d	P[a]
Total no.	11 148	3667 (32.9)	7481 (67.1)			
Year of death						.001
2013	2110 (18.9)	618 (29.3)	1492 (70.7)	1 (Ref)		
2014	2191 (19.7)	718 (32.8)	1473 (67.2)	1.1		
2015	2241 (20.1)	767 (34.2)	1474 (65.8)	1.2		
2016	2290 (20.5)	794 (34.7)	1496 (65.3)	1.2		
2017	2316 (20.8)	770 (33.3)	1546 (66.8)	1.1		
Sex						< .001
Female	454 (4.1)	190 (41.9)	264 (58.2)	1 (Ref)		
Male	10 694 (95.9)	3477 (32.5)	7217 (67.5)	0.8		
Age, y						< .001
18 to < 35	1542 (13.8)	803 (52.1)	739 (47.9)	Ref		
35 to < 55	2400 (21.5)	1011 (42.1)	1389 (57.9)	0.8		
55 to < 75	4504 (40.4)	1381 (30.7)	3123 (69.3)	0.6		
75 to 115	2702 (24.2)	472 (17.5)	2230 (82.5)	0.3		
Mean ± SD	60.1 ± 18.7	53.6 ± 18.3	63.3 ± 18.0		−0.5	< .001
Race/ethnicity						< .001
White	9009 (80.8)	2854 (31.7)	6155 (68.3)	1 (Ref)		
Black	562 (5.0)	179 (31.9)	383 (68.2)	1.0		
Hispanic	284 (2.6)	115 (40.5)	169 (59.5)	1.3		
Other	849 (7.6)	388 (45.7)	461 (54.3)	1.4		
Unknown	444 (4.0)	131 (29.5)	313 (70.5)	0.9		
Married	4571 (41.0)	1443 (31.6)	3128 (68.4)	0.9		.01
Rurality of home address						.003
Urban	7061 (64.2)	2416 (34.2)	4645 (65.8)	1 (Ref)		
Rural	3931 (35.8)	1237 (31.5)	2694 (68.5)	0.9		
Distance from home address to nearest VHA facility, miles	12.8 ± 20.5	12.5 ± 21.9	13.0 ± 19.7		0.0	.01
Region of the United States						< .001
Northeast	1207 (10.8)	372 (30.8)	835 (69.2)	1 (Ref)		
Midwest	2298 (20.6)	852 (37.1)	1446 (62.9)	1.2		
South	4648 (41.7)	1264 (27.2)	3384 (72.8)	0.9		
West	2992 (26.9)	1179 (39.4)	1813 (60.6)	1.3		
Days since most recent VHA encounter	85.4 ± 119.6	48.6 ± 86.5	103.5 ± 129.0		−0.5	< .001
Facility type of most recent VHA encounter						.002
VAMC	6987 (62.7)	2351 (33.7)	4636 (66.4)	1 (Ref)		
CBOC	3122 (28.0)	952 (30.5)	2170 (69.5)	0.9		
Other	1039 (9.3)	364 (35.0)	675 (65.0)	1.0		
Setting of most recent VHA encounter						< .001
Outpatient primary care	3089 (27.7)	763 (24.7)	2326 (75.3)	1 (Ref)		
Outpatient mental health	2172 (19.5)	1104 (50.8)	1068 (49.2)	2.1		
Outpatient emergency department	256 (2.3)	75 (29.3)	181 (70.7)	1.2		

Continued

TABLE 1— Continued

		Suicide Identified by Facility		Effect Size		
	All, No. (Column %) or Mean ± SD	Yes, No. (Row %) or Mean ± SD	No, No. (Row %) or Mean ± SD	RR	Cohen's d	P^a
Outpatient other	5460 (49.0)	1624 (29.7)	3836 (70.3)	1.2		
Inpatient mental health	80 (0.7)	44 (55.0)	36 (45.0)	2.2		
Inpatient non–mental health	91 (0.8)	57 (62.6)	34 (37.4)	2.5		
Diagnoses in previous 12 mo						
Any mental health or SUD diagnosis	6178 (55.4)	2796 (45.3)	3382 (54.7)	2.6		< .001
Any SUD	2508 (22.5)	1245 (49.6)	1263 (50.4)	1.8		< .001
Opioid SUD	478 (4.3)	257 (53.8)	221 (46.2)	1.7		< .001
Bipolar disorder	860 (7.7)	439 (51.1)	421 (49.0)	1.6		< .001
Schizophrenia	383 (3.4)	194 (50.7)	189 (49.4)	1.6		< .001
Depression	3989 (35.8)	1950 (48.9)	2039 (51.1)	2.0		< .001
Anxiety	2252 (20.2)	1077 (47.8)	1175 (52.2)	1.6		< .001
PTSD	2206 (19.8)	1214 (55.0)	992 (45.0)	2.0		< .001
Indication of homelessness in previous 12 mo	687 (6.2)	363 (52.8)	324 (47.2)	1.7		< .001
Indication of suicide attempt in previous 12 mo	471 (4.2)	324 (68.8)	147 (31.2)	2.2		< .001
Per *ICD* diagnosis codes	257 (2.3)	175 (68.1)	82 (31.9)	2.1		< .001
Per SPAN	341 (3.1)	239 (70.1)	102 (29.9)	2.2		< .001
No. of outpatient visit days in previous 12 mo	17.4 ± 23.2	25.4 ± 28.0	13.4 ± 19.3		0.5	< .001
No. of inpatient discharges in previous 12 mo	0.34 ±1.03	0.55 ± 1.33	0.24 ± 0.83		0.3	< .001
Clinical high risk for suicide flag in previous 12 mo	626 (5.6)	432 (69.0)	194 (31.0)	2.2		< .001
Suicide safety plan in previous 12 mo	703 (6.3)	457 (65.0)	246 (35.0)	2.1		< .001
Enrolled with VHA	10 880 (97.6)	3625 (33.3)	7255 (66.7)	2.1		< .001
Missed at least 1 VHA appointment in previous 1 mo	3888 (34.9)	1729 (44.5)	2159 (55.5)	1.1		.001
Mental health screening in previous 12 mo						
Screened for major depressive disorder	6493 (58.2)	2170 (33.4)	4323 (66.6)	1.0		.16
Screened for PTSD	3630 (32.6)	1370 (37.7)	2260 (62.3)	1.2		< .001
Screened for alcohol use disorder	8018 (71.9)	2935 (36.6)	5083 (63.4)	1.6		< .001
Method of suicide						< .001
Firearm	7697 (69.0)	2420 (31.4)	5277 (68.6)	1 (Ref)		
Poisoning	1280 (11.5)	342 (26.7)	938 (73.3)	0.9		
Suffocation	1561 (14.0)	694 (44.5)	867 (55.5)	1.4		
Other	610 (5.5)	211 (34.6)	399 (65.4)	1.1		

Note. CBOC = community-based outpatient clinic; *ICD* = *International Statistical Classification of Diseases and Related Health Problems;* PTSD = posttraumatic stress disorder; RR = relative risk; SPAN = Suicide Prevention Applications Network; SUD = substance use disorder; VAMC = Department of Veterans Affairs Medical Center; VHA = Veterans Health Administration.

[a] *P* value derived from χ^2, *t* test, or Wilcoxon rank sum test comparing facility-identified decedents and nonidentified decedents.

2017. Facilities were more likely to identify suicide deaths of veterans who were younger, had mental health and SUD diagnoses, and who had other recent clinical indicators such as a clinical high risk for suicide flag or previous nonfatal suicide attempt, as compared with veterans without these characteristics. Facility identification differed by method of suicide; suicide deaths involving poisoning were less likely to be ascertained by facilities than those involving other methods. Study results are consistent with findings that from 2002 to 2014 approximately 35% of veteran suicide deaths that occurred within 7 days after VA inpatient mental health discharge were identified in the root cause analysis database.[23]

Study findings document variation in identification by patient

TABLE 2— Adjusted Odds of Facility Identification of Recent Veteran VHA Patient Suicide Decedents: United States, 2013–2017

Predictor	AOR (95% CI)	P
Year of death		.36
2013	1 (Ref)	
2014	1.07 (0.90, 1.25)	
2015	1.17 (0.99, 1.38)	
2016	1.18 (0.98, 1.42)	
2017	1.12 (0.90, 1.39)	
Sex		.68
Female	1 (Ref)	
Male	0.96 (0.80, 1.16)	
Age, y		<.001
18 to <35	1 (Ref)	
35 to <55	0.62 (0.52, 0.73)	
55 to <75	0.40 (0.34, 0.47)	
75 to 115	0.27 (0.21, 0.33)	
Race/ethnicity		.59
White	1 (Ref)	
Black	0.86 (0.72, 1.04)	
Hispanic	0.94 (0.74, 1.20)	
Other	0.93 (0.78, 1.11)	
Unknown	0.95 (0.76, 1.19)	
Married	1.11 (1.03, 1.20)	
Rurality of home address		.50
Urban	1 (Ref)	
Rural	0.96 (0.85, 1.08)	
Distance from home address to nearest VHA facility, miles	1.00 (1.00, 1.00)	
Region of the United States		.11
Northeast	1 (Ref)	
Midwest	1.27 (0.90, 1.78)	
South	0.87 (0.65, 1.17)	
West	1.10 (0.81, 1.49)	
Days since most recent VHA encounter	0.997 (0.996, 0.997)	
Facility type of most recent VHA encounter		.98
VAMC	1 (Ref)	
CBOC	1.01 (0.91, 1.12)	
Other	0.99 (0.83, 1.18)	
Setting of most recent VHA encounter		<.001
Outpatient primary care	1 (Ref)	
Outpatient mental health	1.47 (1.30, 1.67)	
Outpatient emergency department	0.98 (0.75, 1.29)	
Outpatient other	1.05 (0.95, 1.17)	
Inpatient mental health	1.45 (0.83, 2.53)	
Inpatient non–mental health	3.13 (2.09, 4.69)	
Diagnoses in previous 12 mo		

Continued

sociodemographic characteristics, clinical diagnoses, and previous utilization. Stigma surrounding suicide, difficulties of ascertaining intention of death, and differential cause of death misclassification may affect facility ascertainment of suicide deaths. For example, facility identification of suicide deaths may require outreach to a decedent's family or close contacts to confirm cause of death. Suicide is perceived as more stigmatized than other causes of sudden death[31]; thus, identification of deaths as suicides may be challenging if contacts are unavailable or unwilling to disclose suicidal intent.

In addition, determination of intent to die—which is critical to the identification of suicide deaths[32]—can vary by method of death.[21] We found that suicide deaths by suffocation or firearms were more likely to be identified by facilities than those involving poisoning, which includes drug overdoses. Riblet et al. similarly found that suicides involving firearms were most likely to receive root-cause analyses among suicide deaths following VA inpatient discharges.[23] Suicide deaths involving drug overdoses may take longer for coroners or medical examiners to process and classify,[25] which could contribute to facilities being unaware of these suicides.

It is important to note the negative association found between veterans' age and facility identification of suicide deaths. Suicide deaths of older veteran VHA patients were significantly less likely to be documented by facilities than suicides among younger veteran VHA patients. Older decedents are less likely to have an autopsy than younger decedents,[33] and sites may be less informed of suicide deaths among older decedents because natural causes of death are assumed. Furthermore, older age among veterans is

TABLE 2— Continued

Predictor	AOR (95% CI)	*P*
Any SUD	1.01 (0.89, 1.14)	
Bipolar disorder	1.15 (1.00, 1.33)	
Schizophrenia	1.14 (0.92, 1.41)	
Depression	1.44 (1.30, 1.58)	
Anxiety	1.08 (0.98, 1.20)	
PTSD	1.50 (1.35, 1.67)	
Indication of homelessness in previous 12 mo	0.98 (0.80, 1.20)	
Indication of suicide attempt in previous 12 mo		
Per *ICD* diagnosis codes	1.15 (0.82, 1.61)	
Per SPAN	1.17 (0.87, 1.57)	
Number of outpatient visit days in previous 12 mo	1.01 (1.01, 1.01)	
Number of inpatient discharges in previous 12 mo	0.92 (0.87, 0.96)	
Clinical high risk for suicide flag in previous 12 mo	1.69 (1.33, 2.14)	
Suicide safety plan in previous 12 mo	1.28 (1.02, 1.61)	
Enrolled with VHA	1.46 (0.90, 2.38)	
Missed at least 1 VHA appointment in previous 1 mo	1.20 (1.08, 1.33)	
Mental health screening in previous 12 mo		
Screened for major depressive disorder	0.99 (0.90, 1.09)	
Screened for PTSD	0.90 (0.82, 0.99)	
Screened for alcohol use disorder	0.99 (0.87, 1.13)	
Method of suicide		< .001
Firearms	1 (Ref)	
Poisoning	0.45 (0.37, 0.54)	
Suffocation	1.23 (1.09, 1.39)	
Other	0.77 (0.64, 0.93)	

Note. AOR = adjusted odds ratio; CBOC = community-based outpatient clinic; CI = confidence interval; *ICD* = *International Statistical Classification of Diseases and Related Health Problems;* PTSD = posttraumatic stress disorder; SPAN = Suicide Prevention Applications Network; SUD = substance use disorder; VAMC = Department of Veterans Affairs Medical Center; VHA = Veterans Health Administration.

associated with increased reports of loneliness,[34] which could mean fewer contacts to report a suicide death, and older suicide decedents may also be less likely to disclose suicidal intent before death[35] compared with younger individuals. This could contribute to sites being unaware of suicide deaths among older decedents.

Study findings indicate that characteristics of a veteran's recent interactions with the VHA health care system were associated with facility identification and documentation of their suicide death, and that suicide deaths among veteran VHA users without certain characteristics may go unreported. Incomplete capture of suicide decedents without mental health diagnoses or similar clinical indicators is consistent with another study's findings that suicide decedents without psychiatric comorbidities documented on their death certificate had almost 7 times the odds of potential suicide misclassification as decedents with psychiatric indications.[21]

Local facility identification of patient suicide deaths was less complete among suicide decedents who were older, unmarried, had less VHA utilization, whose last encounter was not in a mental health clinic or inpatient non–mental health setting, without clinical indications of high suicide risk or a missed appointment, and whose suicide did not involve firearms or suffocation. Findings offer guidance regarding risk populations that may be underrecognized by facilities. The VHA Suicide Prevention NOW initiative, which focuses on achievable short-term suicide prevention enhancements to complement ongoing activities, encompasses work to support some of the subgroups identified in this analysis, including VHA patients with non–mental health clinical risk indicators.

Strengths and Limitations

A strength of this study is the inclusion of all death certificate–identified suicide deaths among recent veteran VHA users nationwide in the 5-year period 2013 through 2017. A limitation is that the most recent year of mortality data available at the time of analysis was 2017, and the extent to which results are generalizable to ongoing facility ascertainment of veteran VHA user suicides is unknown. Another limitation is that historical facility-level data on SPC staffing was not available. Further work is needed to assess associations between facility suicide prevention staffing, SPC workload and methods of ascertainment, and facility identification of patient suicides. Finally, we note that because of a frequent study outcome, odds ratios calculated in our regression model may overestimate the relative risk.

To our knowledge, this is the first comprehensive assessment of the sensitivity of VHA facility identification of patient suicide mortality. We observed that facility documentation identified only 33% of suicide deaths among recent veteran VHA users, and identification differed by characteristics of decedents and their deaths. Though timely, facility suicide surveillance identifies an incomplete and unrepresentative sample of patient suicide decedents. VA is working to enhance facility identification of suicide deaths; the present findings may support ongoing prevention and surveillance efforts specific to the VHA-using veteran population. Understanding limitations of facility ascertainment will inform interpretation of facility reports and assessment of local suicide prevention efforts. Future analyses will assess the specificity of facility suicide death ascertainment, complementing the present study's assessment of sensitivity, and should also examine heterogeneity of suicide death ascertainment across providers and facilities.

Public Health Implications

Study findings have important implications for VHA facility and regional suicide prevention efforts. Without comprehensive national death certificate indicators, VHA facilities may underestimate the burden of suicide in their patient populations and generate inaccurate profiles of patient suicide decedents. To address these concerns, VHA has developed reporting structures to provide VHA facilities and regional networks with information on counts and rates of suicide among recent veteran VHA users, per MDR death certificate data. Further enhancements are in development to provide sites with information regarding characteristics and utilization patterns of veteran patient suicide decedents, overall and by facility ascertainment.

For non-VHA health systems, reliance on local provider documentation of patient suicide deaths may likewise identify a small and nonrepresentative subset of patient suicide decedents. Findings from Michigan's Henry Ford Health System suggest that internally collected data are best supplemented by death certificate data for comprehensive suicide death surveillance.[16] In the absence of comprehensive death certificate information, local health systems may fail to recognize the burden of suicide in their patient populations or to identify at-risk subpopulations. This may adversely affect resource allocation for suicide prevention and result in missed opportunities to conduct outreach or bereavement support. Study findings highlight the importance of comprehensive health system suicide surveillance based on searches of death certificate data as an essential complement to local facility surveillance efforts. AJPH

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CONTRIBUTORS

K. M. Palframan completed the analyses and led the writing. B. R. Szymanski assisted with the study design and writing. J. F. McCarthy conceptualized the analysis and assisted with writing.

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CONFLICTS OF INTEREST

The authors have no conflicts of interest to disclose.

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Identifying Disparities in Health Outcomes and Mortality for American Indian and Alaska Native Populations Using Tribally Disaggregated Vital Statistics and Health Survey Data

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Objectives. To determine the impact of disaggregated mortality and health surveillance data on the ability to identify health disparities for American Indian and Alaska Native (AI/AN) subpopulations.

Methods. We conducted a systematic review of reporting categories for AI/AN decedents on official death certificates for all 50 US states. Using public data from the 2017–2018 California Health Interview Survey (CHIS), we conducted bivariate and multivariate analyses to assess disparities in health conditions and outcomes for tribally enrolled and non–tribally enrolled AI/AN persons compared with non-Hispanic Whites.

Results. There was no standard for the collection of tribal enrollment data or AI/AN race on death certificates across all 50 states. There were stark differences in the incidence and prevalence of various health risk factors and chronic diseases for the tribally enrolled AI/AN subpopulation, non–tribally enrolled AI/AN subpopulation, and non-Hispanic White comparison group.

Conclusions. The collection of tribal enrollment data in vital statistics and health surveillance systems is necessary to identify and respond to health disparities among AI/AN subpopulations. These efforts must be conducted in partnership with tribal nations and consider Indigenous data sovereignty. (*Am J Public Health*. 111(S2):S126–S132. https://doi.org/10.2105/AJPH.2021.306427)

The American Indian and Alaska Native (AI/AN) population experiences more severe health risks and disparities as compared with other racial and ethnic groups in the United States.[1,2] However, the examination of AI/AN health outcomes beyond race is limited and demands attention, especially at the tribal level. AI/AN tribes are sovereign nations with governance authority predating the founding of the settler colonial state. Citizenship in tribal nations is a political identity akin to citizenship in any nation state.[3] Per federal law, tribal enrollment status refers to the 1 tribe (of 574 federally recognized tribes) with which an individual is registered for service provision.[3] There is extensive variation in criteria for tribal enrollment. Most tribes employ blood quantum, which delineates a minimum amount of tribal blood to be eligible for tribal enrollment.[4] Sovereign tribal nations have a political imperative to provide services to their tribal citizens, including health care. The provision of services extends to the federal government through the federal trust responsibility.[5] Yet this political status is overlooked in health research, in which treatment of the AI/AN population as a homogenous racial or ethnic group prevails.[6,7]

The paucity of research at the intersection of tribal enrollment status and health is largely driven by a lack of data. Without data disaggregated by tribal affiliation and tribal enrollment status, we are missing an important demarcation of difference in health outcomes in the AI/AN population. Tribal affiliation refers to a self-identified ethnic identity, whereas tribal enrollment refers to a self-identified political identity as an enrolled citizen of a sovereign tribal nation. This study seeks to establish the extent to which health disparities are patterned by tribal enrollment status, the limitations of available data, and how Indigenous data sovereignty (IDS) can improve existing data systems so we can better monitor and improve intragroup health outcomes for the AI/AN population. We considered 2 types of data in our analyses: (1) mortality reporting rules by state and (2) health survey data.

First, we explored race and tribal identifiers on death certificates. Previous studies have focused on the persistent racial misclassification of the AI/AN population on death certificates,[8,9] but there is a gap in understanding how not collecting tribal affiliation and enrollment status influences reported death rates and health outcomes for tribally enrolled AI/AN persons. The collection of tribal enrollment status in mortality data is particularly important amid the COVID-19 pandemic given the disproportionate incidence and mortality in the AI/AN population.[10–12] Incomplete data on underlying health conditions, hospitalization, and death for AI/AN persons with COVID-19 is more prevalent than for White persons.[11] While we need more accurate and complete AI/AN race data, we also contend that these data are of limited use to tribal nations because they are responsible for serving their tribal citizens and not the broader AI/AN population. To effectively govern, tribal nations require data on their tribal citizens (living both on and off reservations or tribal homelands). We argue that tribal enrollment status should be collected on death certificates as an exercise of tribal sovereignty. Without these data, the number of tribal citizens who have died from COVID-19 and other causes will remain unknown to tribal nations.

Second, we examined the broader issue of how the omission of tribal enrollment information in existing health reporting and surveillance data sets obscures information about the tribally enrolled population. In the absence of these specific identifiers, one cannot evaluate differences in chronic disease and health care access between the tribally enrolled AI/AN subpopulation and the general AI/AN population. Key national health surveillance systems like the Behavioral Risk Factor Surveillance System and the National Health Interview Survey do not ask tribal affiliation or enrollment status. We used the California Health Interview Survey (CHIS), which asks about tribal enrollment, to compare health outcomes for the tribally enrolled subpopulation, the general AI/AN population, and the non–tribally enrolled AI/AN subpopulation. To our knowledge, it is the only health survey at the state or national level that asks about tribal enrollment. We discuss the significant differences found across these groups for several important health outcomes.

METHODS

We conducted a systematic review of tribal identification categories on death certificates in all 50 states utilizing a 2-part process. First, we employed a Google search using the name of the state plus the following key terms alone or in combination: death, mortality, certificate, record, data, official, blank, sample, example. In cases in which a sample death certificate was not publicly available online, we contacted the state's office of vital statistics by e-mail and then, if necessary, a follow-up phone call. Through this process, we obtained a complete set of sample death certificates for all 50 states. We coded death certificates by the data fields they used to identify the decedent.

Data

We used pooled public-use data from the CHIS for the years 2017 and 2018. We used the adult survey respondents in our analysis. We excluded the child and adolescent survey respondents because they were unlikely to have developed the chronic diseases we examined as outcomes of interest. This data set is one of the longest-running annual health surveys in the country, having started in 2001. The survey is based on a random-dial telephone survey conducted in 7 different languages and is intended to be representative of all California households. Data limitations restricted our analysis to persons who self-identified their race as AI/AN alone. Disaggregated CHIS data for persons who identified with more than 1 race were not publicly available.

American Indian Categorization Variables

The CHIS provides timely health outcomes and health care utilization data for all 58 counties in California. In addition to self-reported race and ethnicity, the CHIS includes a question on self-reported tribal enrollment. The question asks "Are you an enrolled member in a federally or state recognized tribe?" Asking about tribal enrollment is not common practice in health surveys in the United States, which makes the CHIS data set ideal to examine whether health outcomes varied for the AI/AN population by tribal enrollment status. In our analysis, we categorized 3 subpopulations of the AI/AN population: (1) all AI/AN persons in the survey data, which was the most inclusive and largest group (n = 1277); (2) individuals who self-identified as AI/AN and who reported being tribally enrolled, which was the smallest group (n = 287); and (3) the remaining AI/AN population that were not tribally enrolled (n = 990). We included NHWs (n = 25 724) in the analysis as the comparison race group.

Outcomes Variables

To evaluate intragroup health disparities for the AI/AN population, we selected indicators of chronic disease including asthma, type 2 diabetes, obesity, and heart disease. We also examined other behavioral measures such as whether an individual was a smoker and whether a person had visited the emergency department at all or had 4 or more doctor visits in the previous year. The smoker measure indicates whether a person reported smoking 1 or more cigarettes in a typical day. We also coded the variable for having 4 or more doctor visits per year into a binary variable to indicate individuals who may have had a chronic disease or required multiple checkups (4 or more) per year. Finally, the emergency department variable was a binary measure of whether a person reported having gone to an emergency department at any time in the past year. These provided additional measures of the individual's general well-being and health care access and utilization.

Statistical Analyses

First, we conducted a descriptive comparison of means to identify whether various health outcomes were significantly different across the 2 AI/AN subpopulations. Specifically, we used the Pearson χ^2 test to determine whether the average characteristics of the AI/AN-enrolled and AI/AN–not enrolled populations differed from one another. We then performed multivariate logistic regressions on these same health outcomes by the different AI/AN subpopulations to identify how these average health outcomes differed from those of NHWs. In our regression analysis, we examined the difference in health outcomes as compared with the NHW population in California; this is primarily because of a power issue, as we would need much larger sample sizes to identify meaningful effects for most of our outcome measures. We controlled for the following individual-level characteristics in the CHIS data: gender, age, English-language abilities, insurance coverage, poverty levels, educational attainment controls, marital status, employment status, and rural location.

RESULTS

Table 1 shows 5 categories of tribal data that were collected for AI/AN decedents on death certificates for all 50 US states. Thirty-three states asked for the enrolled or principal tribe of the decedent. Three states asked for the specific tribe of the decedent, but not enrollment status. Five states allowed the reporting of more than 1 tribe, but not enrollment status. Only 2 states collected data on Indian reservation or tribal homeland residency. Nine states did not collect any tribal data on their death certificates. This systematic review across all 50 states shows inconsistency in the collection of national mortality data for tribal populations and that tribal enrollment data are rarely collected. Despite the existence of the US Standard Certificate of Death, our results indicate that many states did not employ it. As a result, the mortality rates for tribally enrolled members in any state were not discernable from these data.

Health of American Indian Subpopulations

The absence of tribal enrollment identifiers extends to other data sets that are often used to evaluate health outcomes and the prevalence of diseases. In Table 2, we present the summary characteristics for the sample of the total AI/AN population and 2 AI/AN subpopulations residing in California from the CHIS data set for 2017 and 2018. We also included, for comparison, the characteristics of NHWs in the final column.

TABLE 1— Tribal Data Categories Collected on State Death Certificates: United States, 2017–2018

Category	States
Tribal enrollment or principal tribe	AL, AK, AR, CO, CT, DE, ID, IL, IA, KS, KY, MD, MI, MN, MS, MO, MT, NE, NV, NH, NJ, NC, ND, OR, RI, SC, SD, TN, TX, UT, VT, WA, WV
Specify tribe	FL, NY, VA
Two or more tribes	AZ, MA, NM, OK, WI
Reservation or tribal homeland residence	AZ, WA
No tribe category	CA, GA, HI, IN, LA, ME, OH, PA, WY

TABLE 2— Differences in Average Characteristics by American Indian/Alaska Native Subpopulation: United States, 2017–2018

Variable	AI/AN Total (n = 1277), % or Mean	AI/AN and Enrolled (n = 277), % or Mean	AI/AN and Not Enrolled (n = 990), % or Mean	χ^2 or *t* Test AI/AN Enrolled and AI/AN Not Enrolled	Non-Hispanic White (n = 25 724), % or Mean
Male	46.6	37.2	49.3	7.0	44.3
Rural region	57.0	81.1	50.1	189.5	45.5
Has type 2 diabetes	15.1	20.5	13.6	26.2	10.1
Has asthma	21.7	24.3	21.0	11.5	17.3
Is obese	37.6	47.0	34.9	63.6	24.5
Has heart disease	10.4	14.9	9.1	4.1	13.6
Smoked any cigarettes today	18.7	23.6	17.3	47.1	10.8
Visited the ED in the past year	28.8	29.2	28.6	4.6	24.0
≥ 4 doctor visits past year	42.5	52.9	39.5	10.6	47.5
Age, y	48.0	54.9	46.0	7.4	58.6

Note. AI/AN = American Indian/Alaska Native; ED = emergency department. These observations combine the 2017 and 2018 survey waves of the California Health Interview Survey data. The χ^2 test reports the Pearson χ^2 statistic with 1 degree of freedom. The *t* test in the bottom row compares the 2 means for AI/AN enrolled and AI/AN not enrolled samples from the California Health Interview Survey data.

In the first column, we present the overall characteristics for the total AI/AN population. Slightly less than half were male (46.6%), and 57% lived in a rural region of California. In terms of health outcomes, about 15% had type 2 diabetes, more than 20% had an asthma diagnosis, 37% were obese, 10% had been diagnosed with heart disease, and about 19% were smokers. More than a quarter reported visiting the emergency department in the past year, and about 42% reported going to the doctor 4 or more times in the past year. On average, adult respondents to the CHIS survey were aged 48 years, as shown in the bottom row. Compared with NHWs, the AI/AN population, on average, had a higher prevalence of type 2 diabetes, asthma, obesity, and smoking. The AI/AN population had a lower prevalence of heart disease, on average, than NHWs. The number of emergency department and doctor visits were also slightly higher.

In the next 2 columns, we present the characteristics of the tribally enrolled AI/AN persons and the nonenrolled AI/AN subpopulation. We show the Pearson χ^2 statistic in the column to the right. The enrolled AI/AN population had a higher proportion of women in the sample and were much more likely to be in a rural location. The enrolled AI/AN population also had statistically significantly higher incidences of type 2 diabetes, heart disease, and obesity. They were also much more likely to report having seen a doctor 4 or more times in the past year than the nonenrolled AI/AN population. There did not appear to be strong differences in the prevalence of asthma or ever visiting the emergency department in the past year. Finally, the enrolled population was older than the nonenrolled AI/AN population. Note that all the Pearson χ^2 statistics had *P* values less than .05. Overall, the comparison indicates that the enrolled AI/AN population generally had worse health and well-being characteristics than the nonenrolled AI/AN population in the CHIS data set for California.

Multivariate Regression Results

In Table 3, we provide adjusted odds ratios (AORs) for 8 health indicators controlling for gender, age, English-language abilities, insurance coverage, poverty levels, educational attainment, marital status, employment status, and rural location. The results indicate that the total AI/AN population of adults in California had a higher probability of being diagnosed with type 2 diabetes ($P < .01$), asthma ($P < .05$), and obesity ($P < .01$) than NHWs. For the tribally enrolled AI/AN subpopulation in California, the results resembled our findings from the total AI/AN population; however, being diagnosed with asthma was no longer statistically significant, and 2 additional outcomes were statistically

TABLE 3— Adjusted Odds Ratio Regressions for Health Outcomes by American Indian/Alaska Native Subpopulation: United States, 2017–2018

Variables[a]	Type 2 Diabetes, AOR (95% CI)	Asthma, AOR (95% CI)	Obesity, AOR (95% CI)	Heart Disease, AOR (95% CI)	Any Cigarettes, AOR (95% CI)	ED Visits, AOR (95% CI)	≥ 4 Doctor Visits, AOR (95% CI)
Total AI/AN (n = 27 001)	1.93 (1.62, 2.230)	1.18 (1.02, 1.37)	1.58 (1.40, 1.79)	1.09 (0.89, 1.33)	0.94 (0.79, 1.12)	1.11 (0.97, 1.28)	1.02 (0.91, 1.16)
Tribally enrolled AI/AN (n = 26 011)	2.29 (1.68, 3.13)	1.31 (0.997, 1.72)	2.27 (1.79, 2.88)	1.24 (0.88, 1.74)	1.48 (1.10, 1.99)	1.08 (0.82, 1.41)	1.33 (1.04, 1.69)
Not tribally enrolled AI/AN (n = 26 714)	1.78 (1.45, 2.19)	1.14 (0.96, 1.35)	1.40 (1.21, 1.62)	1.03 (0.81, 1.31)	0.80 (0.65, 0.99)	1.11 (0.95, 1.30)	0.94 (0.82, 1.09)

Note. AI/AN = American Indians/Alaska Natives; AOR = adjusted odds ratio; CI = confidence interval; ED = emergency department. Each regression includes controls for gender, age, year, English-language abilities, insurance coverage, poverty levels, educational attainment controls, marital status, employment status, and rural location and a constant.

[a] Reference group was non-Hispanic White.

significant—being a smoker ($P < .01$) and having 4 or more doctor visits in the past year ($P < .05$). The other difference is that the magnitude of the AOR was larger in all cases as compared with those found in the total AI/AN population. For instance, the total AI/AN population had almost twice the prevalence of type 2 diabetes (compared with NHWs), while the sample of tribally enrolled AI/AN persons had almost 3 times the prevalence of type 2 diabetes (compared with NHWs). We also found a larger prevalence for obesity, being a smoker, and 4 or more doctor visits among the tribally enrolled AI/AN subpopulation. The magnitude of difference between the nonenrolled AI/AN subpopulation and NHWs was smaller than that for the total AI/AN population and the enrolled population, but still significant for type 2 diabetes ($P < .01$), obesity ($P < .01$), and smoking ($P < .05$).

DISCUSSION

Using CHIS data, we show significant differences in health outcomes for subpopulations within the AI/AN population. Because of the paucity of research on intragroup health disparities in the AI/AN population, we do not definitively know why tribally enrolled AI/AN persons experienced higher rates of several chronic health conditions and diseases. There may be underlying behavioral and economic differences that explain disparities in health outcomes across the tribally enrolled and nonenrolled AI/AN population in the United States. For instance, there is significant evidence that poverty levels are higher on reservations than anywhere else in the United States,[13,14] and poverty is an important factor in health outcomes for all populations.[15] To the extent that there are proportionately more tribally enrolled AI/AN persons residing on AI reservation lands, these underlying differences may play a central role in determining health outcomes. In addition, there is ample evidence that access to health care and services are quite limited for the on-reservation population[16,17]; thus, this may be an additional explanatory factor.

Regardless of the underlying reasons why, the incidence and prevalence of risk factors for chronic disease are greater for the AI/AN tribally enrolled subpopulation than for the AI/AN non–tribally enrolled subpopulation. Given that the non–tribally enrolled subpopulation is larger, this means that aggregated data will always be heavily influenced by the non–tribally enrolled AI/AN subpopulation. An important implication is that the vast health disparities between the AI/AN population and other racial groups may be particularly large among tribally enrolled people.

The Case for Disaggregated Tribal Data

In the systematic review of death certificates, we identified inconsistencies in collecting tribal data for AI/AN decedents. Nearly 20% of states collect no tribal data at all, including California, which has the largest number of AI/AN persons of any state and more than 100 tribes.[18] When states do collect tribal data on death certificates, the data are combined for tribally enrolled and nonenrolled subpopulations. Most states rely on the problematic federal standard that asks for “enrolled or principal tribe,” which incorrectly conflates 2 different concepts. "Enrolled" means that a person is an enrolled citizen of a specific tribal nation. "Principal tribe" is a broader capture of an individual's main tribal affiliation, which we also note forces a hierarchical framework onto individuals who have multiple tribal affiliations. There are myriad ways in which this response option could be interpreted by people who are alive, much less by someone on behalf of decedents. Without tribal enrollment recorded on official death certificates, there is no way to assess mortality for tribally enrolled populations on a national level. Missing tribal identifiers and enrollment status on death certificates may ultimately skew mortality rates and inhibit our ability to study disparities.

Tribal Sovereignty

The collection of data on tribal enrollment status must be contextualized within a broader discussion about tribal sovereignty over data. The right of tribal nations to govern the collection, ownership, and use of data on their people, lands, and resources is the foundation of IDS.[19,20] Across the United States, tribal nations are exercising IDS by building data for governance through tribal censuses, surveys, and other instruments.[21] However, there are 2 truths that must also be considered: (1) tribal nations have limited resources to invest in data systems, and (2) the federal government has an obligation to support the collection of accurate and meaningful tribal data as part of the federal trust responsibility.[20,22] Thus, IDS also calls for the alignment of external data systems to meet tribal needs.[23]

We also acknowledge that tensions exist. For example, tribal nations recently challenged the US Census Bureau's efforts to collect tribal enrollment data in the 2020 Census.[24] Tribal nations asserted that doing so would be an encroachment of tribal sovereignty. Ultimately, the Census Bureau ceased any planning for a tribal enrollment question. This could be considered a win for tribal nations in terms of exercising control over data on their tribal citizens. However, there are important potential benefits to expanding the collection of this type of information in official and administrative data collection activities.

Limitations

We note several limitations to this study. First, our findings cannot be generalized beyond California. Second, we acknowledge that self-reported tribal enrollment data are not the same as tribal enrollment data collected and maintained by tribal nations. Future research should evaluate options for data linkage between CHIS and tribal enrollment data controlled by tribal nations. Similarly, the self-reporting of health diagnoses in CHIS data may be underestimating actual prevalence. Because of data limitations, we did not address underlying causes of observed health differences across and between AI/AN subpopulations. Our analyses were also restricted to AI/AN single-race data. Given the continued and pervasive use of blood quantum minimums as criteria for tribal enrollment,[4] we contend that the multiracial AI/AN population would likely include a smaller proportion of enrolled tribal citizens than the AI/AN-alone population.

Public Health Implications

Accurate health statistics are critical to the design and evaluation of health interventions. Our analyses show that official death certificates and national surveys often omit identifiers for AI/AN tribal enrollment. Our analyses also identify significant differences in underlying health conditions and outcomes between the AI/AN population as a whole and the AI/AN tribally enrolled subpopulation. The AI/AN tribally enrolled subpopulation generally experiences a higher burden of chronic diseases.[25] Lacking a tribal enrollment identifier, the incidence and prevalence of health conditions are averaged over a larger AI/AN population, and the specific conditions for tribally enrolled populations are obscured. A policy solution is the development of a federally mandated tribal data standard that includes tribal enrollment status. This standard must not only be designed in partnership with tribal nations but also cogoverned by tribal leaders. It should operate alongside the Office of Management and Budget's Standards for the Classification of Federal Data on Race and Ethnicity.[26] At a minimum, this data standard should apply to all vital statistics records. These measures should also be included in standard demographic characteristics for health and other longitudinal data sets. An example is New Zealand's Iwi (Tribal) Statistical Data Standard, which identifies a process for collecting tribal data by federal agencies for statistical purposes.[27] This is 1 step forward in repairing the broken federal data system that perpetuates the erasure of tribal populations. AJPH

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D. Small-Rodriguez developed the research question and study, conducted the analyses, interpreted the results, and led the writing of the article. R. Akee conducted the analyses, strengthened interpretations of the results, and contributed to the writing of the article. Both authors contributed to article editing and revisions.

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CONFLICTS OF INTEREST

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HUMAN PARTICIPANT PROTECTION

This research used data from secondary sources available in the public domain and was declared exempt from University of California, Los Angeles, institutional review board review per protocol 21-000944. Indigenous data sovereignty research best practices were followed, and no tribally identifiable information was used.

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Office of Management and Budget Racial/Ethnic Categories in Mortality Research: A Framework for Including the Voices of Racialized Communities

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Since its founding, the US government has sorted people into racial/ethnic categories for the purpose of allowing or disallowing their access to social services and protections.

The current Office of Management and Budget racial/ethnic categories originated in a dominant racial narrative that assumed a binary biological difference between Whites and non-Whites, with a hard-edged separation between them. There is debate about their continued use in researching group differences in mortality profiles and health outcomes: should we use them with modifications, cease using them entirely, or develop a new epistemology of human similarities and differences?

This essay offers a research framework for including in these debates the daily lived experiences of the 110 million racialized non-White Americans whose lived experiences are the legacy of historically limited access to society's services and protections. The experience of Latinos in California is used to illustrate the major elements of this framework that may have an effect on mortality and health outcomes: a subaltern fuzzy-edged multivalent racial narrative, agency, voice, and community and cultural resilience. (*Am J Public Health*. 2021;111(S2):S133–S140. https://doi.org/10.2105/AJPH.2021.306361)

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Since the founding of the US government, one of the prerogatives at the federal, state, and local levels has been to sort individuals into racial/ethnic categories for official classification purposes, from birth certificates and the census to death records. The 18th-century dominant narrative used to justify categorizing people by race was a hard-edged binary racial narrative assuming an impenetrable divide between Whites and non-Whites. This hard-edged binary was itself based on the assumption of biological differences between Whites and non-White racial/ethnic groups.[1] Because of their assumed biological inferiority, non-Whites were to be denied access to the full range of services and protections of US society. The powers of the state, from the federal government to local school districts, were used to enforce these racially structured rules limiting non-White individuals' access to the elective franchise, education, jobs, housing, and even marriage partners.[2]

Racialized racial/ethnic groups did not submit passively to being unilaterally categorized and excluded. The shock of becoming racialized stimulated the generation of subaltern racial narratives—the flip side of the dominant hard-edged binary narrative—that helped these groups make sense out of their lived experiences in a racially structured society. These racialized populations used their agency and creativity not only to survive state-sponsored racialization but to remain present and vital in the face of the consequences of externally imposed racial categorizations.[3]

Nearly 230 years later, however, researchers in medicine and health are still directed to sort their research populations into the official Office of Management and Budget (OMB) categories descended from 1790 US Census categories: 1 ethnicity (Hispanic or not Hispanic) and 5 races (White, Black, American Indian/Alaska Native, Asian, Native Hawaiian/Pacific Islander).[4]

The continued use of these racial/ethnic categories causes confusion and anguish. During the pandemic year of 2020, the decennial census once again asked Americans to sort themselves into its racial/ethnic categories. The Black Lives Matter movement erupted while census enumeration, with its antiquated questions about race/ethnicity, was under way. Aware of the legacy of racism inherent in the use of racial/ethnic categories, the American Medical Association declared that these categories were to be considered social constructs, not biological ones, and dedicated itself to combating racism in US society.[5]

Weeks later, a mob violently occupied the US Capitol, some of its members holding aloft symbols of White nationalism and White supremacy, operating under still-prevalent assumptions of biological racial/ethnic differences and non-White inferiority.[6] Even before that, Yudell et al.[7] had published a letter in *Science* with 74 signatories from academic institutions across the country asking the National Institutes of Health to provide leadership on the use of racial/ethnic categories in research. It deplored the unexamined use of these categories in a society still rife with the widely held assumption that racial/ethnic differences were biological. The signatories recommended that the National Institutes of Health, the National Academy of Sciences, and other major science-based organizations convene consensus panels to advise on the use of "racial categories to study" human health.[7(p1313)]

Whatever the future of racial/ethnic categories in mortality and health research—whether they are abandoned, continued, or replaced by some other epistemology of human similarities and differences—we argue that the lived experiences and voices of 110 million Americans who are currently categorized as belonging to one of the traditional non-White racial/ethnic groups must be part of the debates, discussions, and consensus panels. Their legacy of existing for centuries in the racially structured society imposed upon them must be reflected in whatever system of categorization emerges.

Here we offer a research framework to facilitate the inclusion of the lived experiences of non-White racial/ethnic groups, via their subaltern racial narratives, into the discussion of the future of racial/ethnic categories in mortality and health research. Because it is so little known, we describe the development of one of these subaltern racial narratives: the Latino fuzzy-edged, multivalent racial narrative, as experienced in California after its conquest by the United States in 1848. California's Latinos contested efforts to impose on their mixed-race population the dominant US hard-edged binary racial narrative and attendant racial structuring of society. Our framework suggests that researchers may want to understand how these Latinos created their own internally generated resources to combat 170 years of racism.

A RESEARCH FRAMEWORK FOR RACE/ETHNICITY AND HEALTH OUTCOMES

Figure 1 provides a research framework to stimulate discussion about race/ethnicity, social determinants of health (SDOH), and inequalities in mortality and health outcomes that incorporates the lived experience of racialized populations. The figure's top half starts with the dominant US hard-edged binary racial narrative underlying its racially structured society, in which the powers of the state denied full access to the services and protections of the young United States to individuals who were considered non-White and thereby biologically inferior. Initially, the only racialized groups were American Indians and Blacks; during the 19th century, however, these groups came to include Latinos, Asians, and Pacific Islanders as well as mixed-race individuals (mulattos, quadroons, and octoroons).

Our framework illustrates how the US hard-edged binary, enforced by the state, created concentrations of non-White racial/ethnic populations in low-income, low-education, unsafe neighborhoods with poor access to health care, which negatively affected the mortality and health outcomes of these groups.[8] This is recognized in the Healthy People 2030 effort's inclusion of a section on SDOH that "highlight[s] how personal, social, economic and environmental factors can impact people's health."[8]

The bottom half of Figure 1 conceptualizes the lived experience of racialized groups based largely on theories developed by American Indian/Alaska Native scholars of postcolonial indigenous life in the United States.[9] The figure indicates that, before their incorporation into the US dominant racial narrative, precontact racial/ethnic groups had their own narratives about self, society, and history. Once incorporated into the United States and racialized as non-White by the dominant narrative, these racial/ethnic groups were subjected by the power of the state to life in a highly racially structured society that denied them full access to its services and protections.

"Survivance" is a concept developed by American Indian/Alaska Native scholars to describe the ability to live intentionally resilient lives in the face of formidable adversity, such as being

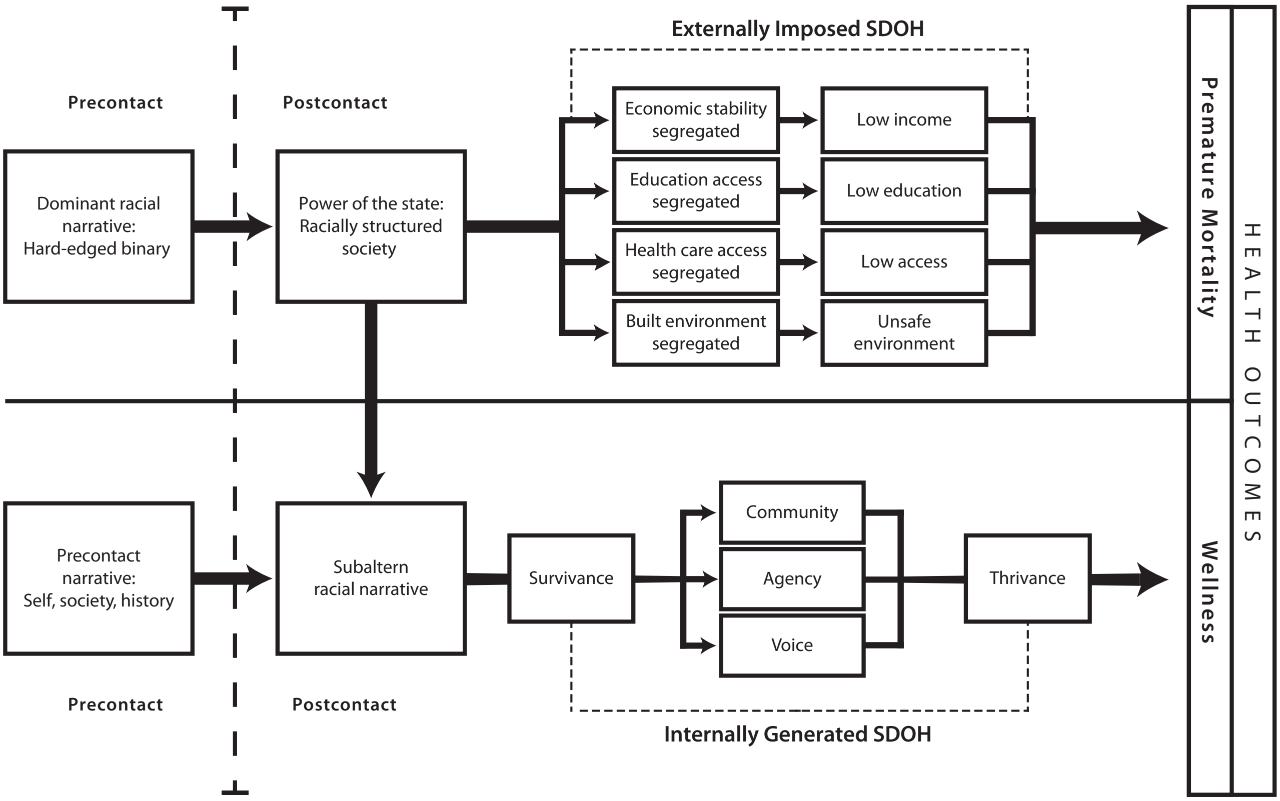

FIGURE 1— A Research Framework: Racial Narratives, Social Determinants of Health, and Health Outcomes

Note. SDOH = social determinants of health.

educated in residential boarding schools designed to strip Indian children of their indigenous culture, including language and oral histories.[10,11] Moreover, community-level narratives of voice and agency can lead to the condition termed "thrivance" by these American Indian/Alaska Native scholars, defined as a daily lived existence beyond mere survival based on some degree of cultural resiliency and prosperity.[12] The subaltern racial narratives created by racialized communities to combat racism—the community, agency, and voice that engender thrivance—may well be internally generated SDOH that also affect health outcomes, albeit in positive ways. These generations of lived experience as racialized minorities in the racially structured society of the United States should be included in whatever constructs are developed in place of current racial/ethnic categories to describe human similarities and differences.

THE DOMINANT US RACIAL NARRATIVE

Grouping people into racial categories has been intrinsic to US data collection since the country's founding. In the 18th, 19th, and early 20th centuries, the Census Bureau sorted respondents into racial categories of interest to the federal government, at times using the results with the explicit intent of proving biological determination in various "races." In 1959, Judge Leon M. Bazile, in the case of *Loving v. Virginia*—a state that prohibited marriage between Whites and Blacks—declared that "Almighty God created the races white, black, yellow, malay and red, and he placed them on separate continents."[13] His statement was informed by, and reinforced, the narrative that racial categories are naturally occurring phenomena.[13] As recently as 1960, the census sorted the US population into a binary set of racial populations: Whites on the one hand and non-White "races" on the other, with the latter including "Black[s], American Indians, Japanese, Chinese, Filipinos, Koreans, Hawaiians, Asian Indians, Malayans, Eskimos, Aleuts, etc."[14]

Binary and Social Determinants of Health

Before the Fifteenth Amendment, in most states only adult White males could vote, so a man's right to vote depended on his racial categorization. Starting in 1850, census forms were standardized, with 3 racial categories: White, Black, and mulatto (most American Indians were deliberately excluded). A person's race was expressed by the concept of "blood." Mulattos had a mixture of White and Black "blood," and these individuals were eventually quantified by the 1890 census as having "three-fifths to five-eighths black blood."[15(p68)]

Researchers who use racial/ethnic categories in their research today as if they were a scientific given should understand that this seeming precision of 19th-century racial categories did not arise from any scientific process. The assumed difference between "White blood" and "Black blood" was never defined. No blood analyses or other scientific tests were involved.[15] People's racial categorizations often were decided by their physical appearance and the guesswork of a temporary federal employee raised with the US hard-edged binary narrative. Adumbrating the early 20th century's "one-drop rule," the 1870 census instructed enumerators that "all persons having any perceptible trace of African blood" should be counted as homogeneously "Negro," despite any other ancestry they might have.[16(p166)] Just as dubiously, anyone appearing White was assumed to have no Black, Native American, or Asian ancestry.[16]

By the 1920s, the eugenics movement sought to pass off such subjective racial categorization as objective science.[2,13] Under its influence, the 1930 US Census invoked a one-drop rule nationally, instructing enumerators to categorize individuals as Negroes "no matter how small the percentage of Negro blood," if they had any at all.[17(p26)] Millions of people suddenly were identified as Black—regardless of how they identified themselves or how previous censuses had identified them—and thereby subjected to restrictions imposed by federal and state laws. Other "racial" categories were added as well, with individuals being sorted into them in similarly arbitrary fashion under the guise of science.

Racially Ambiguous Latinos

Latinos have long proved a conundrum to this US binary system of racial categorization. In the mid-19th century, President James Buchanan described Mexico's population as "Spaniards, Indians, and Negroes, blended together in every variety."[18(p1)] Such racial mixtures would automatically group Mexicans and most other Latinos into the non-White category, and Buchanan declared disparagingly that Mexicans would relate to enslaved Blacks from the United States "on terms of perfect social equality."[18(p1)]

Yet the specific "race" of largely *mestizo* (mixed-race) Latinos historically has been difficult for US institutions to pin down; in censuses before 1930, they often were classified as either White or "other" by default because they fit no other recognized category. The 1930 census officially declared "Mexican" to be a non-White racial category separate from the "white, Negro, Indian, Chinese, or Japanese" races.[17(p26)] It nonetheless conceded that Mexicans were "of a racial mixture difficult to classify."[17(p26)] When in doubt about a Mexican's racial background, the enumerator was instructed that Mexicans were "usually well recognized in the localities where they are found."[17(p26)] That is, they were identified—by Whites—according to whatever version of the US hard-edged binary racial narrative operated locally.

In 1940, however, the Census Bureau reversed itself and instructed enumerators that Mexicans were to be listed as White unless they were "clearly" of Native American or African origin.[19] In the censuses of 1940 through 1970, 6 different new measures were used to identify Latino populations within the US racial binary: Spanish language, Spanish surname, Spanish origin, Spanish heritage, a composite of Spanish language and Spanish surname, or another composite of respondents' birthplace and the birthplace of their parents.[20] Although none of these measures had any objective connection to innate individual biology, the stand-alone unit of Spanish-surnamed individuals was used nonetheless within a narrative that assumed biological determination of racial categories.

SUBALTERN RACIAL NARRATIVES

Non-White individuals and communities have constructed meaning in their lives in the US racially structured society by sharing stories of survival, voice, and agency.[21] These subaltern racial narratives also provide insight into how they experience particular nondisease causes of death. Because it is so little known, we present the subsequent Latino subaltern racial narrative as an example.

Indo-Afro-Oriento-Ibero Population

Humans have lived in Mesoamerica for well over 10 000 years. By 1492, an estimated 25.2 million individuals lived in central Mexico, in large cities, small hamlets, and nomadic encampments, speaking many languages and observing varying customs. The subsequent Spanish conquest of the region unwittingly spread smallpox and other

Eurasian diseases against which the Americas' native inhabitants had almost no immunity, which ravaged indigenous populations in repeated waves. By the end of the 16th century, the indigenous population of central Mexico had shrunk to 1.1 million, a stunning 95% mortality rate.[22]

To fill this human void, the Spanish Crown encouraged its European subjects to resettle in the Kingdom of New Spain. This immigration included some clandestinely Jewish and Muslim populations fleeing the Inquisition.[23] The Crown also brought people from Africa to labor as slaves in the fields, *obrajes* (workshops), and domestic service.[24] In 1565, an annual Spanish trade fleet began to sail from Acapulco to Manila and back; for the next 250 years, its return trips to New Spain brought in people from the Philippines and other regions of Asia.[25]

In New Spain, these people from around the world lived, worked, and produced children together, resulting in a population combining a dazzling variety of ancestry from indigenous America, Africa, Asia, and Europe. Food, music, languages, and spiritual practices from around the world mingled for more than 2 centuries, creating an Indo-Afro-Oriento-Ibero experience of Western society that undergirds modern civil society in Mexico and Latin America.

In 1769, members of this racially and ethnically mixed population began bringing their version of Western society to California, building a string of settlements along the coast from San Diego to San Rafael. When Mexico declared independence from Spain in 1810, its new government abolished slavery and declared racial equality in citizenship, abrogating the irrelevant racialized categories extant under Spanish rule. These categories were officially eliminated from Mexican censuses during the 19th century.[26]

Contesting the US Hard-Edged Binary

From the 1803 Louisiana Purchase to the acquisition of Puerto Rico in 1898, the United States has absorbed preexisting Latino populations, whose experiences with the US hard-edged binary racial narrative during the 20th and 21st centuries have been relatively similar to those in California.

In 1848, the United States defeated Mexico and took territory comprising what is now the US Southwest, including California. The US government then moved to impose institutions intended to replicate there its hard-edged binary racial structuring of society. Coming from a multiethnic culture that had rejected racialized categorization, mixed-race Latinos were appalled at the prospect of living as second-class citizens in a country that supported slavery and White supremacy. At the California State Constitutional Convention in 1849, Latino delegates offered a different vision of how to structure society, defining citizenship according to devotion to shared civic values of freedom and equality instead of race. Initially, they had some success.[27] California was declared a bilingual state, with all laws, decrees, and regulations to be published in both English and Spanish.[28] Mexico's earlier abolition of slavery was upheld,[27] and California was admitted to the Union as a free state in 1850.

But the most hotly contested issue at the 1849 convention was the proposed limitation of voting to White males only. Adoption of that limitation would have led to many members of California's mixed-race population losing the universal male suffrage they had enjoyed under Mexican law. A recently arrived New Yorker, representing San Francisco, warned fellow Euro-American delegates that "the word 'white' ... was not generally understood in this country [i.e., California], though well understood in the United States."[27]

Yet when a Latino delegate pushed for a precise, objective definition of the term "White," Euro-American delegates could not supply one. They answered vaguely that it was a word used to exclude "the inferior races of the human species" from voting and that "White" was used in all other state constitutions of the time.[27] After a furious, inconclusive debate over how to measure an individual's "Whiteness," the majority of White delegates voted, over the objections of the minority Latino delegates, to leave the matter of determining a person's race to the courts at some future time. Not completely convinced that the new (to Latinos) jury system would protect Latinos' voting rights, Pablo de la Guerra of Santa Barbara put through an amendment that would allow some full-blooded Indians, under certain circumstances, to become voting citizens.[27]

Fuzzy-Edged, Multivalent

Since their inclusion in the US racial/ethnic category system in 1980, under the label of "Hispanic," Latinos have contested their racialization in responses to census questions about race. Since the 1980 census, all respondents have been asked whether their ethnicity is Hispanic or non-Hispanic. They are then asked to indicate their race. As of 2010, they could indicate whether they were of 2 or more races. Yet Latinos tend to be confused when asked to categorize themselves into 1 of the 5 official OMB groups (White, Black, American Indian/Alaska Native, Asian,

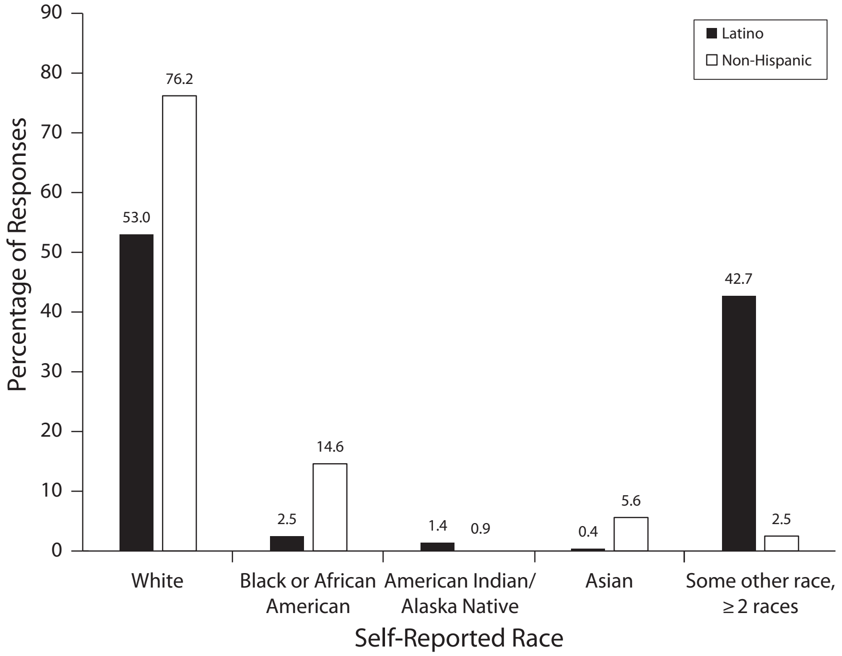

FIGURE 2— Latino and Non-Hispanic Responses to the Census Question on Race: United States, 2010

Source. Humes et al.[29]

Native Hawaiian/Pacific Islander). Non-Hispanic respondents evidently have accepted (even if grudgingly) participation in the US traditional racial categorization and generally declare themselves to belong to one of the OMB's racial categories (Figure 2). Only 2.5% do not see themselves in those categories and indicate that they are "some other race" or "more than one race."

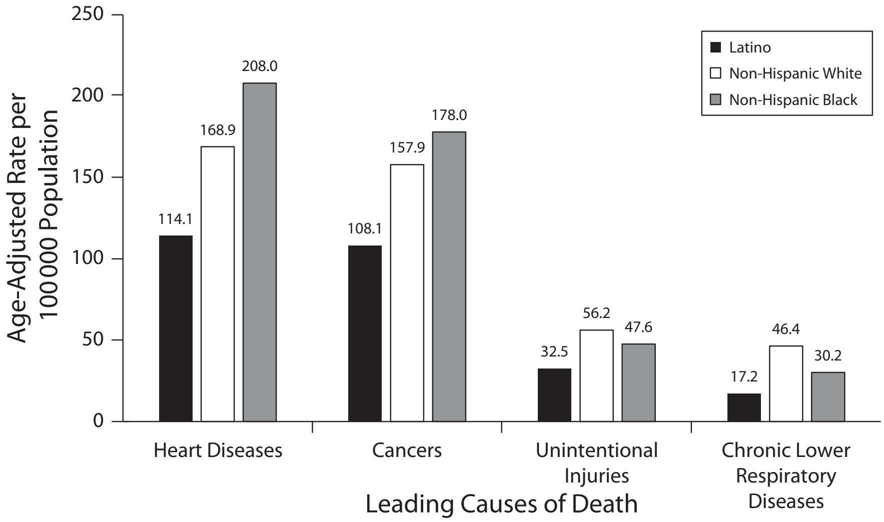

FIGURE 3— Age-Adjusted Rates of the Top 4 Leading Causes of Death, by Race and Hispanic Origin: United States, 2017

Source. Kochanek et al.[33]

Those identifying as Hispanic, however, exhibit a very different response pattern to the question about race. Nearly half (42.7%) state that they are "some other race" or "two or more races."[29] In a 2015 Pew survey, nearly one third of Latinos described themselves as *mestizo*, a multivalent term indicating a mixture of 2 or more races, generally indigenous and Iberian but potentially also including African or Asian ancestry.[30] This "fuzzy-edged" concept lacks any hard-edged dividing line supposedly separating the different ancestries, in contrast to the hard-edged US distinction between White and non-White. Furthermore, although 53% of Latinos state that they are White,[29] they may not mean it in the biologically deterministic racialized sense that modern White nationalists mean it. For some Latinos, the category "White" may simply mean that they feel they are Americans: citizens of the United States.[31]

The Latino Epidemiological Paradox

In 2015, the Office of Minority Health of the US Department of Health and Human Services stated that "many racial and ethnic minority populations experience higher rates of disease and premature death than Whites."[32] Yet the National Center for Health Statistics recently released mortality data for 2017 illustrating a paradox that Latinos present for health researchers.[33] Figure 3 shows age-adjusted death rates for the top 4 causes of death in the United States (heart diseases, cancers, unintentional injuries, and chronic lower respiratory diseases) in the 3 largest racial/ethnic groups: Latinos, non-Hispanic Whites, and non-Hispanic Blacks.

These data show that the Latino age-adjusted death rate is significantly lower than that of Whites for all 4 causes of death, a paradoxical finding given that Latinos have far lower levels of income, education, and access to care than Whites. These paradoxically lower age-adjusted Latino mortality rates were also observed in California over a 14-year period spanning 1999 to 2011.[34] Moreover, paradoxically low Latino infant mortality rates were observed over a 41-year period (1970–2011) in the same state.[34] These paradoxically positive Latino mortality outcomes, despite the SDOH of poverty, low education, and poor access to care, strongly suggest the influence of other SDOH internally generated but not yet captured by health researchers.

Internally Generated Social Determinants of Health

More than 20 years ago, in attempting to identify the mechanisms behind the Latino epidemiological paradox, Scribner suggested that group-level effects might be more important in understanding Latino mortality and health than “genetic, biological or socioeconomic factors operating at the individual level.”[35(p304)] Researchers have begun calling this particular nondisease, nonbiological group-level effect on mortality the “barrio advantage.”[36] In our research framework (Figure 1), Scribner’s suggested group-level effects may be the result of Latino survivance, agency, voice, community, and thrivance undergirded by the Latino subaltern racial narrative.

Similarly, other racialized groups—Blacks, American Indians/Alaska Natives, Asians, and Native Hawaiians/Pacific Islanders—have had to make sense out of their experience in the US racially structured society. Individual and collective stories told in their various subaltern racial narratives may better inform researchers about their perspectives on nondisease, nonbiological threats to their patterns of mortality and health.

CONCLUSIONS

As argued by Yudell et al.,[7] discussions and debates are needed with respect to use of the OMB’s current racial/ethnic categories, which originated in 18th-, 19th-, and early 20th-century biologistic models of racial differences, in mortality and health research. It is likely that they will need to be replaced by some other epistemology for describing human similarities and differences. In this essay, we have urged that the lived experiences of non-White racial/ethnic communities—as expressed in subaltern racial narratives, survivance, agency, voice, community, and thrivance—be part of these discussions so that the effects of 230 years of racialized experience are included in whatever new system of categorization is developed to explain group differences in patterns of mortality and health outcomes in the diverse population of the United States. AJPH

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D. E. Hayes-Bautista conceptualized the article and wrote the original draft. M. Bryant contributed investigation on race categories in hospital records and formal analysis. M. Yudell contributed investigation on eugenics in science and writing review and editing. T. M. Hayes-Bautista contributed formal analysis of findings. K. Partlow contributed investigation on Black experiences with racial categories. A. B. Popejoy contributed writing review and editing. E. Burchard contributed investigation on racially ambiguous experiences. P. Hsu contributed investigation on Asian American and Asian–Latino experiences.

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CONFLICTS OF INTEREST

The authors have no conflicts of interest to disclose.

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No protocol approval was necessary for this research because no human participants were involved.

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Measuring All-Cause Mortality With the Census Numident File

Keith Finlay, PhD, and Katie R. Genadek, PhD

Objectives. To assess the quality of population-level US mortality data in the US Census Bureau Numerical Identification file (Numident) and describe the details of the mortality information as well as the novel person-level linkages available when using the Census Numident.

Methods. We compared all-cause mortality in the Census Numident to published vital statistics from the Centers for Disease Control and Prevention. We provide detailed information on the linkage of the Census Numident to other Census Bureau survey, administrative, and economic data.

Results. Death counts in the Census Numident are similar to those from published mortality vital statistics. Yearly comparisons show that the Census Numident captures more deaths since 1997, and coverage is slightly lower going back in time. Weekly estimates show similar trends from both data sets.

Conclusions. The Census Numident is a high-quality and timely source of data to study all-cause mortality. The Census Bureau makes available a vast and rich set of restricted-use, individual-level data linked to the Census Numident for researchers to use.

Public Health Implications. The Census Numident linked to data available from the Census Bureau provides infrastructure for doing evidence-based public health policy research on mortality. (*Am J Public Health*. 2021;111(S2):S141–S148. https://doi.org/10.2105/AJPH.2021.306217)

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Mortality is a critical outcome in public health surveillance. The COVID-19 pandemic has demonstrated the importance of placing individual death events within their social, economic, and geographic contexts. For example, to identify if Black and Hispanic individuals are overrepresented in COVID-19 mortality rates, high-quality race and ethnicity data linked to mortality records are necessary. To identify why Black and Hispanic individuals are overrepresented, we may need a much richer set of data, potentially going back in time. To study how frontline health workers are impacted by COVID-19 mortality, death records must be linked with occupation or employer data. These kinds of person-level data linkages are often made by public health researchers in smaller settings, but doing so at the population level and in a timely way during a public health emergency is unprecedented.

The Census Bureau's Data Linkage Infrastructure is an ecosystem of survey and administrative records that are linked at the person, address, and business levels. The files are de-identified and made available anonymously to researchers in a restricted-access setting. This infrastructure is an excellent environment to study mortality because it holds full-population death data from the Social Security Administration's Numerical Identification file (SSA Numident). While the SSA Numident has historically suffered from underreporting of deaths and incorrect death dates, the Social Security Administration's (SSA's) efforts to improve death monitoring have greatly enhanced the mortality information in the SSA Numident file.[1–3] Moreover, the Census Bureau has actively analyzed, curated, and documented the death information in the file, working with SSA to disseminate high-quality and complete death data through the Census Bureau's Numerical Identification file (Census Numident).

The linkage of Census Bureau surveys, administrative data, business data, and death data allows for rich analyses of the relationships between all-cause mortality and demographic characteristics, socioeconomic factors, educational attainment, family structure, residential location, migration, program participation, and early life conditions. While research use of SSA death data is not new,[4] the research possibilities for measuring relationships between social and economic determinants of all-cause mortality with the data available through the Census Bureau are vast and generally underutilized.[5,6] These data are currently accessible to researchers working on approved projects within the Federal Statistical Research Data Center (FSRDC) network.

In this article, we introduce the mortality data in the Census Numident and explain the origin and creation of the data file. To assess the quality of the data, we compared mortality estimates from the Census Numident with the primary population-level published statistics for the United States collected from states by the National Center for Health Statistics and published by the Centers for Disease Control and Prevention (CDC). The availability and linkage of these mortality data to other data held at the Census Bureau for research is also described, as well as how researchers can access these data. We show that the Census Numident is an excellent source to study all-cause mortality, especially for analyzing social determinants, understanding neighborhood context, making evidence-based decisions, and even studying pandemics.

SOCIAL SECURITY ADMINISTRATION AND CENSUS NUMIDENT FILES

SSA uses the SSA Numident to maintain records of Social Security Number (SSN) holders. Although SSNs were created and issued starting in 1936, electronic tracking of SSN information in the Numident began in 1972. The Numident contains all interactions individuals have with SSA related to SSNs, including information on SSN applications, claim records, death information, and requested changes to SSN information. There are now more than 1 billion transactions within the SSA Numident for approximately 518 million living and deceased SSN holders in the SSA Numident.

The Census Bureau obtains SSA Numident data from SSA to improve Census Bureau survey and decennial census data, perform record linkage, and conduct research and statistical projects. To facilitate the use of the SSA Numident data, the Census Bureau processes quarterly updates from SSA transaction records to create a person-level research file that includes the history of individual-level interactions with the SSA Numident. The Census Bureau calls this processed file the Census Numident. Like the SSA Numident, the Census Numident is a cumulative file. The most recent vintage of the Census Numident is the largest and most up-to-date version, and researchers should use the newest vintage for mortality research.

The Census Bureau assigns a unique, anonymous identifier, called a Protected Identification Key (PIK) to all individuals in the Numident based solely on the SSN. All names and SSNs are removed from the Census Numident file, and the resulting data file, with the PIK added, is then made available to Census Bureau staff and external researchers for approved Census Bureau production and research projects. PIKs are used to link records at the person level over time and across survey and administrative records.

The scope of information in an individual's Census Numident record varies based on when the individual received an SSN, and if the individual has interacted with SSA, such as for a name change. In general, most records include date of birth, place of birth, sex, race/ethnicity, date of SSN application, dates and types of SSA interactions, and the reported date of death (month, day, and year) if deceased. (The variables are listed in Table A, available as a supplement to the online version of this article at http://www.ajph.org.)

DEATH INFORMATION IN THE NUMIDENT

SSA administers the US Old-Age, Survivors, and Disability Insurance program, often referred to as "Social Security." The death information included in the SSA Numident is collected by SSA for the purposes of administering the Old-Age, Survivors, and Disability Insurance program, and the way this information is collected and managed has changed over time. Death information is obtained through several sources including first-party reports of death from family members and representatives and verified third-party reports from friends, state government offices, the Centers for Medicare and Medicaid Services, the Department of Veterans Affairs, and the Internal Revenue Service.

SSA began maintaining death information using electronic methods in 1962[7] and integrated those records into the Numident when it was created.[8] Information on deaths before 1962 is often incomplete or missing.[8] Previous research has shown that because SSA was primarily focused on deaths of claimants, the Numident had greater death coverage for deaths occurring at older ages than deaths occurring at younger ages.[9] However, since 2005, SSA has improved its methods for monitoring deaths by using a new system for electronically registering deaths, the Death Information Processing System. In 2019, SSA undertook the Death Data Improvement Initiative following a report from the Government Accountably Office in 2013 about errors in the death data[1] and 2 reports from the Office of the Inspector General about missing and incorrect deaths in the

Numident.[2,3] This resulted in more records with death information and updates to death information for deaths going back to 1960. The SSA Numident is now SSA's single system of record for death information.[10]

The data included in the SSA Numident and, thus, the Census Numident are limited to SSN holders, and their deaths can occur anywhere, including outside of the United States. The SSA Numident also contains much more complete death records than the oft-used public Death Master File,[11–14] which has always been a subset of the SSA Numident death records. (See "Death Data Related to the Census Numident" available in the supplement to the online version of this article at http://www.ajph.org for more information.) The Death Master File has deteriorated in coverage since a reinterpretation of privacy statutes in 2011, which limited the inclusion of state records.[15–17] While SSA death reports are considered to be measured with some error,[18] they have been used for research on all-cause mortality even before these recent data quality improvements.[19–22]

METHODS

We measured all-cause mortality using the Census Numident by simply counting the deaths based on the recorded year of death. For the primary analyses, we used the Census Numident date of death, which is the most recent death information for a person from the SSA Numident. We benchmarked all-cause mortality estimates using vital statistics mortality estimates from the CDC, the primary source of mortality data for the United States. The CDC data are compiled from death certificates from state vital statistics offices that have been provided to the National Center for Health Statistics. We use the Compressed Mortality Files from CDC WONDER for the years 1980 to 2016. For 2017 to 2018, we used the CDC WONDER public data tool, and for 2019 to 2020, we used counts from the provisional tables.[23] We also compared the Census Numident death counts before 1980 to published mortality estimated from the CDC Compressed Mortality data and the National Vital Statistics System historical tables.[24] The CDC data, including the restricted-use National Death Index, provide date of death, age, sex, race, cause of death, and place of death.

The CDC data have a different universe than the Census Numident, but they provide a useful comparison to assess the coverage of the Numident file for measuring mortality. The CDC-published estimates only include deaths occurring in US states and are not limited to SSN holders, whereas the Census Numident includes deaths of SSN holders dying abroad and in US territories but does not include deaths occurring in the United States for those without an SSN. Thus, almost all the deaths in the United States will appear in each of the files. The difference in counts between the files depends on both error in the data-generating process and the difference between the number of deaths occurring to SSN holders outside of US states and the number of deaths occurring to individuals within the United States without an SSN.

We further benchmarked the Census Numident to the CDC data by performing comparisons of weekly death estimates, age of death, and place of death. Although the Numident does not contain place of death, we were able to proxy for location of death by identifying almost all individuals' most recent residential locations from the Census Bureau's Master Address File - Auxiliary Reference File (MAF-ARF), which is a data file created using information from population-level censuses and administrative records, including annual Medicare enrollment and individual tax filings. Thus, we can approximate death counts by state using records that were assigned a location in the MAF-ARF. Additional analyses of the death counts by race and sex are shown in Tables D and E (available as supplements to the online version of this article at http://www.ajph.org). By comparing the Census Numident to the CDC data in more detail, we can assess data quality and identify any shortcomings of mortality records in the Census Numident.

RESULTS

Figure 1 shows yearly mortality estimates from the Census Numident and the CDC from 1940 to the present (the underlying estimates can be found in Table B, available as a supplement to the online version of this article at http://www.ajph.org). The yearly comparison shows that the Census Numident has more deaths than the CDC estimates in each year from 1997 forward. Going back in time, the Census Numident coverage declines slightly each year until 1985, when the Census Numident contains 95% of the death counts from the CDC and remains around there until 1980. Before 1980, the Census Numident death counts drop steadily until 1967, when they are 75% of the CDC counts. The coverage then drops precipitously, reaching down to 32% of the CDC count in 1960 and continues to decline steadily to under 10% in 1940. This large decrease in deaths captured by the Census Numident occurs directly before the creation of the electronic system for capturing deaths.

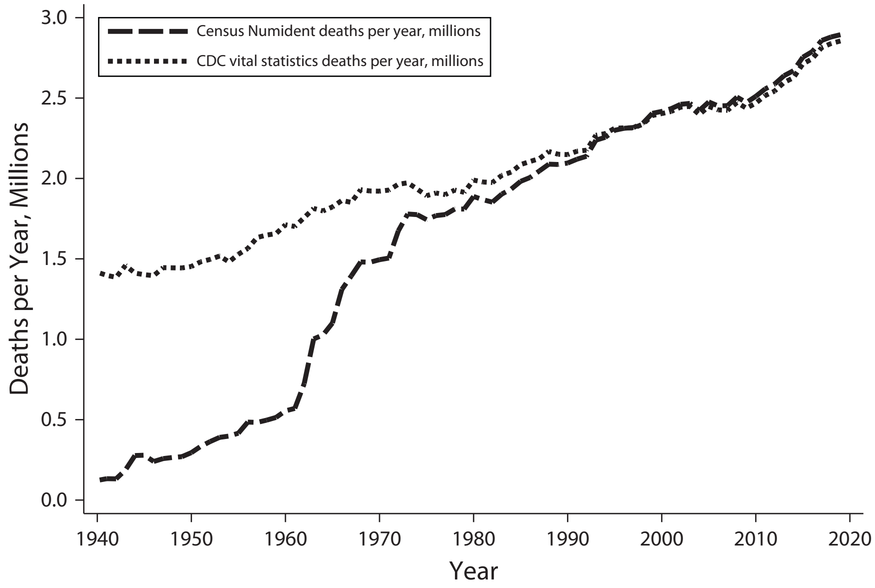

FIGURE 1— Coverage of Deaths per Year in the Census Numident vs Centers for Disease Control and Prevention (CDC) Vital Statistics: United States, 1940–2019

Source. Census Numident calculations from vintage 2020Q4. All Census Numident results were approved for release by the US Census Bureau, authorization number CBDRB-FY21-ERD002-009. CDC counts were obtained from the CDC WONDER database.

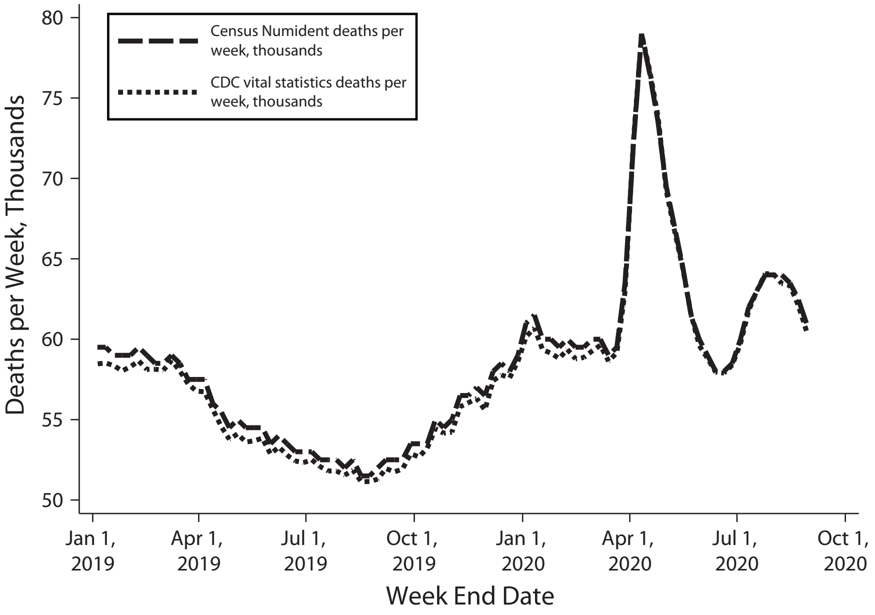

FIGURE 2— Coverage of Deaths per Week in the Census Numident vs Centers for Disease Control and Prevention (CDC) Vital Statistics, January 2019–September 2020

Source. Census Numident calculations from the vintage 2020Q4. All Census Numident results were approved for release by the US Census Bureau, authorization number CBDRB-FY21-ERD002-009. CDC counts were obtained from the CDC WONDER database.

The yearly mortality counts suggest that the Census Numident is similar to the vital statistics from CDC on average. Likewise, the weekly mortality estimates from the Census Numident and CDC from 2019 and 2020 are nearly identical. Figure 2 shows the weekly death counts from the Census Numident and the CDC from January 2019 through August 2020. The weekly estimates are nearly the same over the period, both showing the large spike from the COVID-19 pandemic. The weekly coverage of the Census Numident, when compared with the CDC data, ranges from 97% in the final week to 102% in the first week of 2019. These results show that the death data in the Census Numident are accurate and timely. Further analyses show that, in 2019, most deaths appear in the Census Numident within 7 days after the death occurs. This has improved since 2000, when more than half of the deaths were added to the SSA Numident 13 or more days following the death. (Detailed statistics about reporting delay can be found in Table F, available as a supplement to the online version of this article at http://www.ajph.org.)

Table 1 shows death counts that occurred between 2000 and 2018 by age at the time of death from both the Census Numident and the CDC. Columns 2 and 3 show the percentage of the total deaths occurring for individuals at those ages within each of the files and column 4 shows the ratio of Numident to CDC deaths. The Census Numident has a larger share of deaths for people of unknown ages (death records missing birth dates or exact date of death) and fewer deaths for individuals aged younger than 1 year than the CDC data. The infant deaths captured by CDC and not the Census Numident are likely from live births that do not result in SSN issuance because of deaths occurring shortly

TABLE 1— Mortality Counts by Age at Death: United States, 2000–2018

Age	Census Numident (% of Total)	CDC Vital Statistics (% of Total)	Numident/CDC
< 1 y	231 000 (0.47)	489 447 (1.02)	0.47
1–4 y	82 000 (0.17)	84 362 (0.18)	0.97
5–14 y	114 000 (0.23)	114 051 (0.24)	1.00
15–24 y	583 000 (1.20)	600 236 (1.25)	0.97
25–34 y	842 000 (1.73)	869 313 (1.80)	0.97
35–44 y	1 483 000 (3.04)	1 506 617 (3.13)	0.98
45–54 y	3 358 000 (6.88)	3 365 173 (6.99)	1.00
55–64 y	5 899 000 (12.09)	5 830 574 (12.10)	1.01
65–74 y	8 586 000 (17.59)	8 351 622 (17.34)	1.03
75–84 y	12 830 000 (26.29)	12 514 521 (25.98)	1.03
≥ 85 y	14 730 000 (30.18)	14 446 308 (29.99)	1.02
Missing	65 000 (0.13)	4 151 (0.01)	15.66
Total	48 803 000	48 176 375	1.01

Note. CDC = Centers for Disease Control and Prevention. Missing age indicates that age on date of death could not be calculated because the observation was missing the day of the month the death occurred. The Census Numident counts are rounded per Census Bureau Disclosure Review Board guidelines.

Source. Census Numident calculations from vintage 2020Q4. All Census Numident results were approved for release by the US Census Bureau, authorization numbers CBDRB-FY21-ERD002-004 and CBDRB-FY21-ERD002-009. The CDC vital statistics counts were obtained from the CDC WONDER database.

after births.[25] The share of deaths in each of the age categories is remarkably similar across the files in the other age categories. For ages older than 75 years, the Census Numident has a slightly larger share of total deaths falling between ages 75 and 84 years and age 85 years and older.

We were able to use the MAF-ARF to obtain the deceased's state of residence during the year of death (or location during most recent year in the MAF-ARF before death) for 92% of the total deaths in the Census Numident from 2010 to 2018. While some of the individuals not linked to the MAF-ARF were because they lived abroad, most were likely not linked because of incompleteness in the MAF-ARF (though we cannot distinguish between these 2 groups). The state-level comparison of the Census Numident to the CDC estimates presented in Table 2 support this as the Census Numident death counts are more than 90% of the CDC counts in most states, but there are 11 states with coverage between 85% and 90%, and Hawaii has the lowest coverage rate at 72% of the CDC count. These states in particular suggest that this undercount is not comprised fully of deaths from residents without SSNs, and while it is possible to estimate location of death, these data are incomplete for studying state-level deaths.

The results from benchmarking the Census Numident to the CDC vital statistics show that the population-level death counts are similar across the data sources, even though each has a slightly different universe. The timing and quality of the Census Numident data have improved over time, and the death data in the Census Numident are a high-quality source for measuring all-cause mortality.

DISCUSSION

The results show that the Census Numident accurately estimates all-cause mortality for the United States. While these data do not include cause of death, they become valuable research tools when linked at the person level to other data held at the Census Bureau. Moreover, these data are available to researchers working on approved projects through the FSRDC network.

Linking Census Bureau Data to the Census Numident

Data sets available within the Census Bureau's Data Linkage Infrastructure are linkable to the Census Numident and allow researchers to measure the relationship between mortality and demographic characteristics, educational attainment, economic well-being, neighborhoods, migration, public policy, program participation, disability, general health, and many other potential social determinants of mortality. Researchers are already using 2000 and 2010 decennial census data and American Community Survey (ACS) data linked to Census Numident birthplace information to proxy for early life location and exposure.[26] Moreover, researchers can link individuals to the 1940 Decennial Census,[27] and soon to all decennial censuses from 1940 to 2020, to understand the impacts of early life conditions and place-based exposure on mortality.[28]

As described previously, individual records in the Census Numident are assigned PIKs based solely on SSN. Data from the Census Numident are then included in the Census Bureau's Reference Files, which are used within the Census Bureau's Person Identification Validation System to assign PIKs

TABLE 2— State-Level Mortality Counts: United States, 2010–2018

States	Census Numident, No.	CDC Vital Statistics, No.	Numident/ CDC
Hawaii	69 000	95 857	0.720
Montana	73 500	85 849	0.856
West Virginia	173 000	201 324	0.859
Vermont	44 500	51 428	0.865
New Mexico	137 000	157 207	0.871
Mississippi	243 000	277 152	0.877
Kentucky	363 000	408 180	0.889
Louisiana	348 000	390 890	0.890
Arkansas	248 000	277 887	0.892
Arizona	424 000	474 748	0.893
Idaho	103 000	115 165	0.894
Oregon	278 000	309 821	0.897
Oklahoma	312 000	347 505	0.898
North Dakota	50 000	55 689	0.898
North Carolina	699 000	775 916	0.901
South Carolina	372 000	412 329	0.902
Utah	136 000	150 439	0.904
Maine	112 000	123 730	0.905
Alabama	415 000	458 389	0.905
Texas	1 512 000	1 654 386	0.914
Washington	434 000	474 541	0.915
Georgia	639 000	697 003	0.917
Missouri	486 000	527 724	0.921
New York	1 258 000	1 365 987	0.921
Tennessee	540 000	585 743	0.922
Nevada	185 000	200 165	0.924
Alaska	34 500	37 288	0.925
Ohio	970 000	1 046 075	0.927
Massachusetts	466 000	501 959	0.928
Indiana	514 000	553 409	0.929
Kansas	217 000	233 479	0.929
Virginia	537 000	577 702	0.930
Rhode Island	82 000	88 214	0.930
Colorado	295 000	316 578	0.932
California	2 115 000	2 269 249	0.932
Nebraska	135 000	144 777	0.932
Pennsylvania	1 096 000	1 173 367	0.934
Illinois	885 000	946 599	0.935
New Hampshire	97 000	103 632	0.936
Iowa	246 000	262 491	0.937
Wisconsin	427 000	453 863	0.941
New Jersey	611 000	649 343	0.941
South Dakota	64 000	67 896	0.943
Wyoming	39 500	41 826	0.944

Continued

probabilistically to other Census Bureau data using information such as SSN, name, address, birthdate, and sex.[29] All names and SSNs are removed after PIK application so that data access by researchers remains confidential. Any data file that has been assigned PIKs can be linked at the individual level to the Census Numident. While the assignment of PIKs to data sets is probabilistic, reviews of the Person Identification Validation System show that PIK assignment has resulted in high-quality linkages with minimal error.[30,31] Because the Census Numident is restricted to SSN holders, linkages to the other data sets are also limited to SSN holders. The data files are restricted-use and available to researchers upon approval for specified projects.

The Census Bureau surveys that can be linked anonymously at the person level to the Census Numident vary in the type of data and population coverage. The 2000 and 2010 Decennial Censuses capture precise location, household structure, and basic demographic information for all residents in the United States, and roughly 90% of the person records in these files have been assigned a PIK. Additional detailed information on educational attainment, federal program participation, migration, employment, income, disability, fertility, veteran status, and dwelling characteristics are available for nearly 20% of Census 2000 (known as the long-form sample). Since 2000, the ACS has been fielded to nearly 3% of the population yearly, and it includes questions similar to the Census 2000 long form. Various Census Bureau surveys also have PIKs assigned to them, and they include more detailed questions on health, well-being, and life experiences for smaller samples. These data files include the Current Population Survey Annual Social and Economic

TABLE 2— Continued

States	Census Numident, No.	CDC Vital Statistics, No.	Numident/ CDC
Minnesota	356 000	376 234	0.946
Michigan	797 000	841 628	0.947
District of Columbia	41 000	43 234	0.948
Delaware	72 000	75 720	0.951
Maryland	400 000	419 668	0.953
Connecticut	259 000	270 646	0.957
Florida	1 621 000	1 690 238	0.959
Total	22 031 000	23 860 169	0.923

Note. CDC = Centers for Disease Control and Prevention. The Census Numident counts are rounded per Census Bureau Disclosure Review Board guidelines.
Source. Census Numident calculations from vintage 2020Q4. All Census Numident results were approved for release by the US Census Bureau, authorization numbers CBDRB-FY21-ERD002-004 and CBDRB-FY21-ERD002-009. The CDC counts were obtained from the CDC WONDER database.

Supplement, the Survey of Income and Program Participation, the National Crime Victimization Survey, and the National Survey of College Graduates.

In addition to survey data, the Census Bureau Data Linkage Infrastructure holds administrative data from federal agencies, state and local governments, and third parties that have had PIKs assigned at the person level. These data include Medicare and Medicaid enrollment data, the Criminal Justice Administrative Records System, program data from the Department of Housing and Urban Development, and state-level administrative records from the Supplemental Nutrition Assistance Program and Special Supplemental Nutrition Program for Women, Infants, and Children. Researchers can also access the MAF-ARF, which links individuals with PIKs to address-level residential locations from 2000 to the present using comingled survey and administrative data, and the Census Household Composition Key, which links PIKs of parents to PIKs of children born from 1997 to the present.

Finally, the Census Bureau's Longitudinal Employer-Household Dynamics program integrates employer and employee data from state unemployment insurance records with other business and demographic data. Employees in the Longitudinal Employer-Household Dynamics data can be linked by PIK to the Census Numident. And the businesses in the Longitudinal Employer-Household Dynamics data can be linked to the many economic microdata files created by the Census Bureau for research including the Business Register, the Economic Census, and other establishment surveys.

Access and Use of the Census Numident File

The Census Numident file is available to researchers through the FSRDCs, along with all the other data described previously, for use on approved projects. The FSRDC network currently includes 32 physical research centers at universities and research institutions, and many projects are currently approved for virtual access.[32] Researchers can apply to use the Census Numident data through the standard Census Bureau FSRDC application process, which starts by contacting the closest FSRDC.[33]

The Census Numident is updated quarterly with new SSA transactions in March, June, September, and December. As discussed, there are slight delays in death reporting to SSA and inclusion in the Numident updates. At the median, dates of death now appear in the Census Numident a week after death events. About 25% of deaths take at least 2 weeks to appear, and the slowest 5% take 6 weeks to appear.

Public Health Implications

Complete, high-quality mortality data are essential for public health monitoring. Linking mortality data to survey and administrative data allows public health researchers to understand the relationships between mortality and demographic characteristics, social factors, economics, and geographic settings. Large linked data are also essential to evaluate and create evidence-based public health policy. We have shown that the Census Numident is a high-quality, population-wide mortality data source and that the Census Bureau's Data Linkage Infrastructure provides novel linkages to perform groundbreaking research on mortality. The use of these data to measure the relationships between social and economic determinants of all-cause mortality will improve our understanding of public health and health policy in the United States. AJPH

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CONFLICTS OF INTEREST

The authors have no conflicts of interest to disclose.

HUMAN PARTICIPANT PROTECTION

No human participants were used in this research, and this research was approved by the US Census Bureau.

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Tracking Pandemic Severity Using Data on the Age Structure of Mortality: Lessons From the 1918 Influenza Pandemic in Michigan

Siddharth Chandra, PhD, and Julia Christensen, BA

Objectives. To test whether distortions in the age structure of mortality during the 1918 influenza pandemic in Michigan tracked the severity of the pandemic.

Methods. We calculated monthly excess deaths during the period of 1918 to 1920 by using monthly data on all-cause deaths for the period of 1912 to 1920 in Michigan. Next, we measured distortions in the age distribution of deaths by using the Kuiper goodness-of-fit test statistic comparing the monthly distribution of deaths by age in 1918 to 1920 with the baseline distribution for the corresponding month for 1912 to 1917.

Results. Monthly distortions in the age distribution of deaths were correlated with excess deaths for the period of 1918 to 1920 in Michigan ($r = 0.83$; $P < .001$).

Conclusions. Distortions in the age distribution of deaths tracked variations in the severity of the 1918 influenza pandemic.

Public Health Implications. It may be possible to track the severity of pandemic activity with age-at-death data by identifying distortions in the age distribution of deaths. Public health authorities should explore the application of this approach to tracking the COVID-19 pandemic in the absence of complete data coverage or accurate cause-of-death data. (*Am J Public Health*. 2021;111(S2):S149–S155. https://doi.org/10.2105/AJPH.2021.306303)

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As of February 22, 2021, the COVID-19 pandemic had claimed more than 500 000 lives in the United States.[1] According to Centers for Disease Control and Prevention mortality data,[2] it is likely that the 1-year total number of deaths attributable to COVID-19 will approach or even exceed 20% of the total number of deaths in the United States in 2020. While a precise count of the lives lost because of COVID-19 is impossible to compute, obtaining accurate estimates of the death toll across the globe is a matter of great importance for public health. Such estimates will enable us to better understand the epidemiology of COVID-19 and associations between various public health measures and pandemic outcomes.

Unfortunately, high-quality data on COVID-19 cases and COVID-19–related deaths are scarce. In most countries, the infrastructure for testing and diagnosing the disease and for accurately recording deaths by cause are inadequate. These gaps underscore the need for alternate and indirect methods to ascertain the severity of the pandemic across the world.

The influenza pandemic of 1918 to 1920 has become the benchmark against which the COVID-19 pandemic is compared. This influenza pandemic was the single most devastating pandemic in recent history, causing at least 50 million deaths,[3] including approximately 675 000 in the United States.[4] An effect of high mortality from the 1918 influenza and COVID-19 pandemics is their distortionary impact on demographic aggregates, including births[5,6] and deaths. In the case of COVID-19, mortality has been especially severe among elderly people, with case-fatality rates increasing with age.[7–9] In the case of the 1918 influenza, mortality was disproportionately high among young adults aged approximately 20 to 40 years (Figure 1).[10–12]

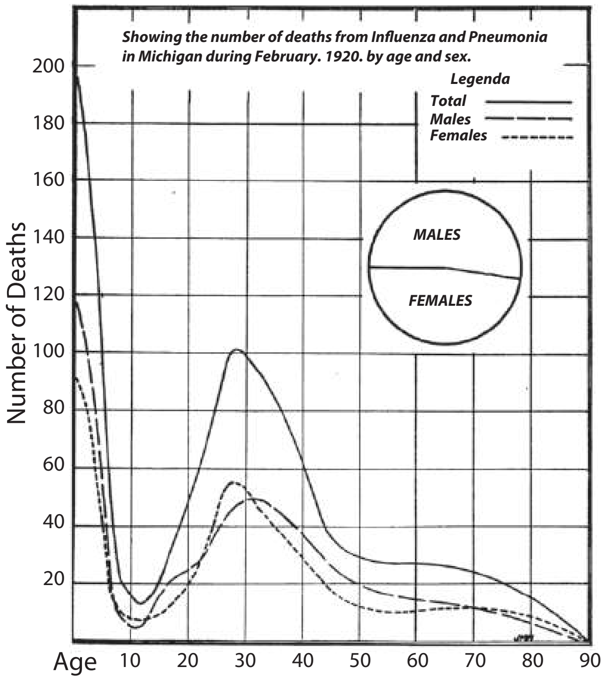

FIGURE 1— Number of Deaths From Influenza and Pneumonia in Michigan During February 1920 by Age

Source. Michigan Department of Health.[20] Digitally enhanced by Camille North.

Our aim, therefore, was to explore the degree to which distortions in the age structure of mortality that bear the signature of a pandemic disease can serve as an indicator of pandemic severity. To do so, we analyzed the age structure of mortality during the successive waves of excess mortality in Michigan over the 36 months comprising 1918 to 1920 and answered 3 questions: (1) Did age–mortality distributions for any of the 36 months show distortions consistent with the 1918 influenza? (2) Did the months identified in question 1 correspond with waves of excess mortality? (3) Is there an association between the severity of waves of excess mortality and the degree to which the age–mortality curve is distorted in comparison with the baseline age–mortality pattern? Our analysis demonstrated that the answer to each of these 3 questions is affirmative.

BACKGROUND

The age–mortality pattern of the 1918 influenza pandemic was "unique"[13] in that peak mortality was experienced by young adults in the 20- to 40-year age range,[14–16] leading researchers to characterize the pandemic as having a W-shaped age–mortality curve in contrast to the U-shaped curves usually seen in seasonal influenza.[11,17–19] Various theories have been advanced to explain this unusual pattern, including antigenic history (protective of older people), comorbidity with tuberculosis, heightened immune response (among younger adults), and T-cell dysregulation because of previous infection by another pathogen.[19] Michigan followed the W-shaped age–mortality pattern (Figure 1, for example).[20]

Some studies have found variations in infant and elderly mortality that do not fit the generalized W-shaped curve; this is likely attributable to small sample size (among the elderly)[21] and high baseline mortality (among children younger than 5 years) from noninfluenza causes.[22] Young adults, however, consistently experienced disproportionately high mortality. This "distinguishing feature"[11] creates a signature age–mortality curve (despite variations in infant and elderly mortality), which can be used as a proxy to identify possible pandemic-associated waves in the continuing absence of direct viral evidence.[11]

Studies variously identify the ages or age ranges of peak excess mortality or significant excess mortality during the 1918 influenza pandemic as 15 to 25,[13] 15 to 44,[23–25] 18 to 42,[17] 20 to 29,[22] 25 to 44,[14,18] and 28 years.[19] New York City, like Michigan, experienced multiple pandemic waves from spring 1918 to April 1920, with notably elevated mortality for ages 5 to 39 years[14] during all waves. Several previous studies have also identified elevated mortality risk among young adults during the spring 1918 wave,[13,14,23] suggesting that this was a herald wave caused by the same pathogen as the deadly fall 1918 wave. Studies on the winter 1919 wave and any 1920 waves have mixed age–mortality profiles.

METHODS

Our approach involved, first, computing monthly excess deaths in Michigan. Next, we analyzed the monthly age distributions of mortality for each of 36 months during the pandemic years (1918–1920) in relation to the baseline distribution corresponding to the month in question for 6 years preceding the pandemic (1912–1917) to look for shifts in the age composition of mortality consistent with the signature W-shaped pattern of the pandemic. We limited the pandemic years to 1918 to 1920 because the consensus in previous studies is that the pandemic did not extend beyond 1920.[26] Third, we compared the timing of spikes in excess mortality with the timing of spikes in distortion of the age structure of mortality to ascertain whether they coincided. Finally, we used time-series methods to study monthly mortality by age group to identify the sources of distortion of the age structure of mortality in 1918 to 1920 during times of high distortion.

The data for this study contained monthly age distributions of deaths in Michigan between 1912 and 1920, for a total of 9 years (108 months). The variety of age ranges described in the previous section represents regional differences in reporting,[22] complicating both detailed age-distribution analysis and cross-study comparison. Reflecting the emphasis on vulnerable age categories, the Michigan Department of Health reported deaths in 4 age categories: younger than 1 year, 1 to younger than 5 years, 5 to younger than 65 years, and 65 years and older. This categorization allowed us to establish levels of young adult mortality that distinguished the 1918 pandemic, thereby enabling us to identify the likely influenza-associated excess mortality waves in Michigan coinciding with the pandemic.

The total number of deaths recorded for the entire period was 392 497.[27] Notably, the 3 vulnerable age groups (i.e., <1 year, 1 to <5 years, and ≥ 65 years) accounted for approximately two thirds of all total deaths (66%) even though they accounted for a disproportionately small portion of an average lifespan. For the pandemic years, the corresponding percentage had fallen to only 51%.

We computed monthly excess deaths in Michigan by seasonally adjusting the raw data on monthly deaths using the PROC X12 algorithm in SAS. [28] This algorithm adjusts a time series for regular cyclical fluctuations corresponding to a 12-month (seasonal) cycle using an iterative algorithm.[28,29] We used the additive variant of the algorithm. Given the presence of outliers during peak months of the pandemic, we also used the outlier detection feature, which eliminates distortions introduced into the algorithm when outliers are included in the computations.[28]

To compare the monthly age distributions of mortality in 1918 to 1920 with the prepandemic baseline, we aggregated the numbers of deaths in each age category by month for the years 1912 to 1917 to obtain the baseline age distribution of mortality. Next, we conducted 2 tests comparing the age distribution of mortality for each of the 36 months between January 1918 and December 1920 with the baseline age distribution for the corresponding month. One test, designed for ordered data, was the Kuiper test,[30] which modifies the better-known Kolmogorov–Smirnov test[31] by according greater weight to frequencies at the ends of the distribution (i.e., infants and the elderly). Given the nature of the data, in which the age categories at the ends of the distribution are of particular importance, we selected this test in preference to the standard Kolmogorov–Smirnov test. Briefly, the Kuiper statistic, K, is defined as[30]

$$K = D_{+} + D_{-} \qquad (1)$$

where D_{+} is the supremum of the difference between the cumulative distribution functions of the 2 distributions and D_{-} is the infimum of the difference between the 2 cumulative distribution functions. We chose not to use the asymptotic Kuiper 2-sample test statistic because the scale factor for that statistic would be distorted for months with extremely high excess mortality, yielding an artificially high correlation.[32] We also compared the distributions using the standard χ^2 goodness-of-fit test.

Finally, we examined the evolution of excess deaths within each age category over time. Using the PROC X12 algorithm in SAS,[28,29] we adjusted the time series for regular seasonal patterns, thereby extracting the trend and irregular components of the age-specific counts of deaths. This approach complements the previous cross-sectional analysis with a time-series dimension.

RESULTS

Distortions in the age structure of mortality closely tracked excess mortality coinciding with the severity of the 1918 influenza pandemic. Figure 2a shows estimates of monthly excess mortality in 1918 to 1920. Figure 2b shows the χ^2 and Kuiper test statistics comparing the monthly age distributions of mortality for 1918 to 1920 with the baseline age distribution of mortality for that month. The similarity between the 2 graphs is striking. The peaks of excess mortality in Michigan (Figure 2a) coincide neatly with peaks in the Kuiper statistic and the χ^2 statistic (Figure 2b). The Kuiper test of the null hypothesis of no difference between the distribution for pandemic months and the corresponding baseline months is rejected for the following 9 months of high excess mortality: April, October, November, and December 1918; January and February 1919; and January, February, and March 1920. Notably, the null hypothesis was rejected for only 1 other month during this 36-month time period, July 1918. The correlation coefficient between the Kuiper statistic and excess mortality for the 36 months from January 1918 to December 1920 was 0.83 ($P<.001$). Even after the removal of 4

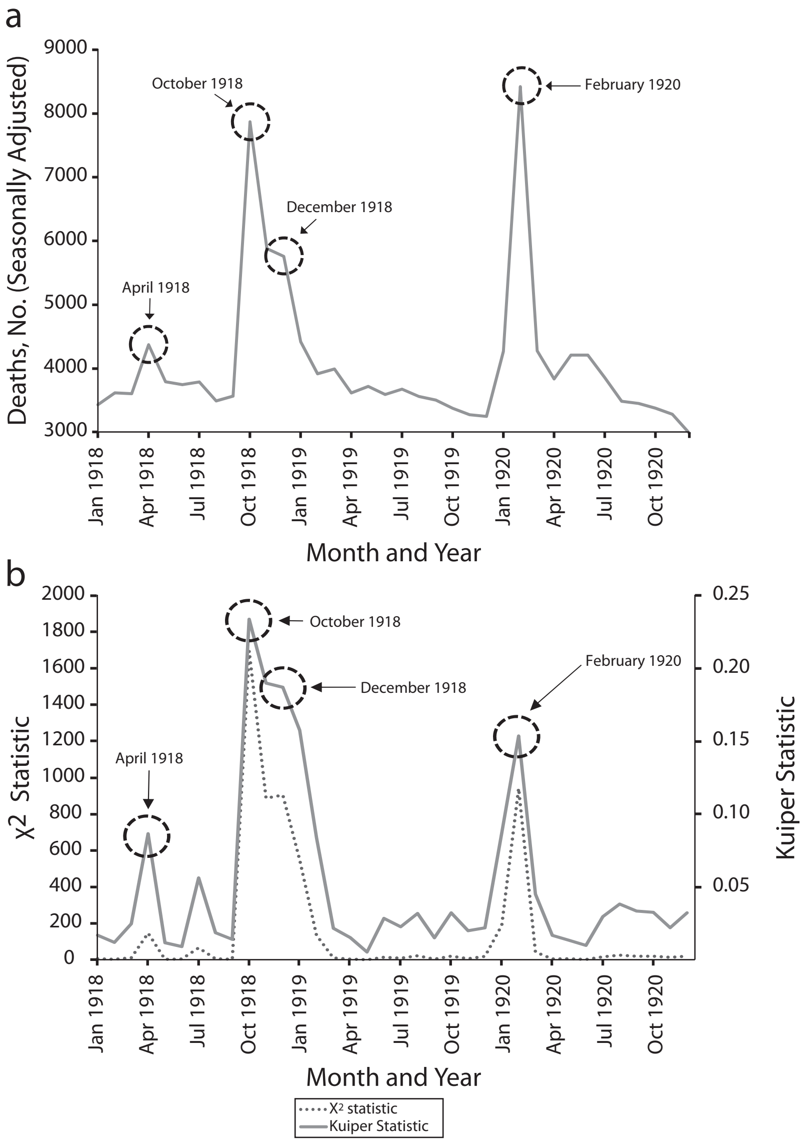

FIGURE 2— **Monthly (a) Number of Deaths and (b) Test Statistics Comparing Age Distribution of Mortality vs Baseline: Michigan 1918–1920**

Note. Data were seasonally adjusted.

outliers for excess mortality (October–December 1918, February 1920), which is in any case not warranted because of their substantive importance, the coefficient was 0.52 ($P = .003$).

Table 1 demonstrates that distortions in the age structure of mortality for all 9 months of high excess mortality were similar. Without exception, deaths among infants and elderly people were proportionately lower during these peaks compared with normal years, and deaths among younger adults were proportionately higher.

Finally, Figure 3, showing seasonally adjusted deaths over time for each of the 4 age groups, reveals an interesting phenomenon. While the first peak of excess mortality (spring 1918) was accompanied by a noticeable spike in deaths among younger adults, the second peak of 1918 (fall and winter) showed spikes in deaths for younger adults and children, and the February 1920 peak resulted from spikes in excess mortality for all 4 age groups.

DISCUSSION

The results motivate 3 key observations. First, the timing of waves and peaks of excess mortality closely track distortions in the age structure of mortality. The high correlation between the degree to which the age–mortality distribution deviates from the monthly baseline and our estimates of excess pandemic-associated mortality suggests that these distortions, measured by the Kuiper statistic, may, under the right conditions, be a good measure of pandemic activity. These conditions include (1) accurate and representative, though not necessarily complete, data on the age structure of mortality; (2) timing that coincides with a known pandemic; and (3) the absence of other events that may distort the age structure of mortality.

Second, distortions in the age structure of mortality in Michigan uniformly resulted from a higher proportion of younger adults dying. This observation aligns with the widely observed W-shaped age structure of mortality in Michigan and other locations during the pandemic.

And third, with each successive peak of excess mortality, increasing numbers of people outside the worst-affected age group (ages 5 to < 65 years) were being affected. Figure 3 demonstrates that successive peaks of excess mortality expanded across age categories until, during the early 1920 wave, a spike in excess mortality was noticeable in each of the 4 age categories. This phenomenon raises the question of whether the 1920 wave was caused by the same or a different pathogen or, possibly, by separate pandemic and seasonal strains

TABLE 1— Age Distribution of Deaths During Months of High Excess Mortality: Michigan, 1918–1920

	Percentage of Total Deaths by Age Category			
Time Period[a]	0 to < 1 Year	1 to < 5 Years	5 to < 65 Years	≥ 65 Years
April 1918	14.35	5.24	52.54	27.87
April baseline	17.27	6.07	43.88	32.78
Variation from baseline	−2.92	−0.83	8.66	−4.91
October 1918	10.64	7.75	66.31	15.30
October baseline	18.06	5.98	44.70	31.26
Variation from baseline	−7.42	1.78	21.61	−15.96
November 1918	11.39	9.23	61.44	17.94
November baseline	15.88	5.27	46.40	32.44
Variation from baseline	−4.50	3.96	15.04	−14.50
December 1918	11.02	7.36	61.96	19.66
December baseline	16.03	5.08	45.53	33.36
Variation from baseline	−5.01	2.28	16.43	−13.70
January 1919	13.48	7.01	56.87	22.64
January baseline	16.34	5.06	43.06	35.55
Variation from baseline	−2.85	1.95	13.81	−12.91
February 1919	15.98	7.14	49.75	27.13
February baseline	17.15	5.25	43.24	34.36
Variation from baseline	−1.16	1.88	6.51	−7.23
January 1920	15.15	7.42	49.42	28.02
January baseline	16.34	5.06	43.06	35.55
Variation from baseline	−1.19	2.36	6.36	−7.53
February 1920	13.88	8.85	55.01	22.26
February baseline	17.15	5.25	43.24	34.36
Variation from baseline	−3.27	3.60	11.77	−12.10
March 1920	16.16	6.83	46.40	30.61
March baseline	17.52	5.70	43.01	33.77
Variation from baseline	−1.36	1.13	3.39	−3.16

[a] Baseline monthly data computed for the period 1912 to 1917.

simultaneously circulating among the population.[17] Alternatively, if, indeed, each wave was caused by the same H1N1 virus, why were varying cross-sections of the population being affected by each successive wave?[22] Was the virus evolving, was the surviving population developing immunity,[19,22,25,33] or was some behavioral factor such as the return of American troops to the United States in the aftermath of World War I responsible?

Limitations

The results of this study should be interpreted keeping in mind several limitations. First, the original data on deaths are limited to 4 age groups, ruling out a fine-grained analysis of age-related impacts. However, this level of aggregation enables us to focus on traditionally vulnerable age segments of the population. Furthermore, given the variation of excess mortality across age groups within the young adult category, as seen in earlier studies,[13,14,17,18,22,23] the data also demonstrate that aggregation does not appear to weaken the association between excess mortality and distortion of the age structure of mortality. A second limitation is the use of mortality rather than morbidity data to capture pandemic severity. This choice was made in line with the large literature on the 1918 pandemic that has used mortality because of the superior quality of such data. A third limitation is the excess mortality computation to attribute deaths to the pandemic, a necessary step because of the absence of accurate diagnostic testing at the time. This study follows previous work on the 1918 influenza pandemic using excess mortality to infer pandemic-associated excess deaths.[34] A fourth limitation of this study is the open question of whether the 1920 wave of influenza-like illness was caused by the same novel influenza virus as the 1918 to 1919 waves.[35]

Conclusions

In this study, we combined the findings of the cross-sectional analyses of age distributions of mortality with the time-series analyses of mortality by age group to characterize the age structure of mortality during the successive waves of excess mortality coinciding with the timing of the 1918 influenza pandemic in Michigan. We found a striking pattern of similarity between the degree to which the age structure of mortality for high-excess-mortality months between 1918 and 1920 deviated from the monthly norm and the magnitude of excess mortality during those months. The highly synchronous pattern of these distortions with excess mortality (Figures 2a and 2b) suggests that

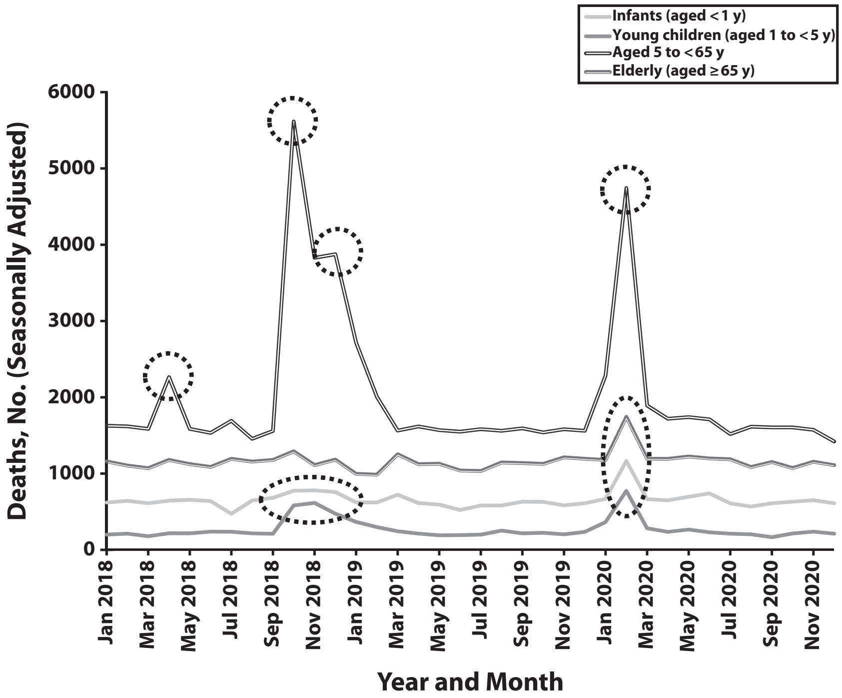

FIGURE 3— Monthly Deaths by Age Group: Michigan, 1918–1920

information about the age structure of mortality may convey valuable information about pandemic activity.

An important implication of this study is that, even with incomplete data coverage or in the absence of detailed cause-of-death data during pandemics such as the ongoing COVID-19 pandemic, it may be possible for researchers to detect and estimate pandemic activity by using age-at-death data to identify distortions of the age structure of mortality consistent with elevated pandemic-associated mortality. Given the inadequacy of data collection, reporting, and diagnostic systems in many areas, an indirect method such as this may enable us to better characterize the epidemiology of pandemics, thereby strengthening our understanding of them and ways in which to mitigate their devastating consequences. With this in mind, we hope that future research will closely examine the age structure of mortality of the COVID-19 pandemic and explore the use of distortions in this age structure to identify locations around the world where the pandemic may have struck unnoticed, unrecorded, or underestimated. AJPH

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CONTRIBUTORS

S. Chandra conceptualized and designed the project, collected and analyzed the data, interpreted the results, and co-wrote all sections of the article. J. Christensen assisted in conceptualization and design of the project, collection and analysis of the data, and interpretation of the results, and co-wrote all sections of the article.

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CONFLICTS OF INTEREST

Neither author has conflicts of interest to report.

HUMAN PARTICIPANT PROTECTION

The research reported in this article did not involve human participants. Therefore, institutional review board approval was not needed.

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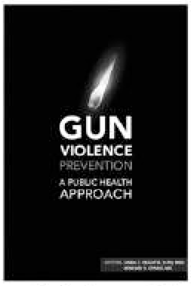

The Unrecognized Mortality Burden of Genetic Disorders in Infancy

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Objectives. To determine how deaths of infants with genetic diagnoses are described in national mortality statistics.

Methods. We present a retrospective cohort study of mortality data, obtained from the National Death Index (NDI), and clinical data for 517 infants born from 2011 to 2017 who died before 1 year of age in the United States.

Results. Although 115 of 517 deceased infants (22%) had a confirmed diagnosis of a genetic disorder, only 61 of 115 deaths (53%) were attributed to *International Classification of Diseases*, *10th Revision* codes representing congenital anomalies or genetic disorders (Q00-Q99) as the underlying cause of death because of inconsistencies in death reporting. Infants with genetic diagnoses whose underlying causes of death were coded as Q00-Q99 were more likely to have chromosomal disorders than monogenic conditions (43/61 [70%] vs 18/61 [30%]; $P < .001$), which reflects the need for improved accounting for monogenic disorders in mortality statistics.

Conclusions. Genetic disorders, although a leading cause of infant mortality, are not accurately captured by vital statistics.

Public Health Implications. Expanded access to genetic testing and further clarity in death reporting are needed to describe properly the contribution of genetic disorders to infant mortality. (*Am J Public Health*. 2021;111(S2):S156–S162. https://doi.org/10.2105/AJPH.2021.306275)

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Genetic disorders and congenital anomalies are considered the leading cause of infant mortality in the United States,[1,2] based on data from the National Center for Health Statistics (NCHS) at the Centers for Disease Control and Prevention.[1] These data are generated from death certificates, on which a medical care provider specifies a series of events leading to death, starting from the most immediate cause (e.g., pulmonary hypoplasia) and ending with the underlying cause of death (e.g., congenital diaphragmatic hernia). These death certificates are translated by the NCHS into codes using the *International Classification of Diseases, 10th Revision* (*ICD-10*), and these codes are grouped to generate national mortality statistics.[3] A computer algorithm is used to code entries from a death certificate, assign the underlying cause of death, and produce multiple cause mortality data.

These data consistently demonstrate that the *ICD-10* codes most frequently assigned as the underlying cause for infant deaths (approximately 20%) are in the Q00-Q99 category, which encompasses “congenital malformations, deformations and chromosomal abnormalities.”[1] This category includes well-defined syndromes such as Down syndrome (Q90.9) and congenital anomalies such as cystic kidney disease (Q61) and congenital cardiac and vascular malformations (Q20-Q28). Although these data are often interpreted to mean that genetic disorders are the leading cause of infant mortality,[4–6] many genetic disorders do not have their own *ICD-10* codes, may not be included on the death certificate, or may not be reported and coded accurately because of errors at the provider level[7] or at the level of the NCHS.[8] The nature and scope of this misclassification and possible underestimation of the mortality burden of genetic disorders remain unknown, although a previous study identified that *ICD-9* codes (the predecessor to *ICD-10*) as reflected in hospital discharge records were correct for only 18% of the live- or stillborn infants coded as having major anomalies because of both provider misdiagnosis and flaws in the coding system.[9] Therefore, the objective of this study was to analyze a diverse cohort of infant deaths spanning several years, identify deaths occurring in the setting of a confirmed genetic disorder, and subsequently review the *ICD-10* codes used to report these deaths at the national level to evaluate their accuracy.

METHODS

We identified a cohort of 573 infants born over a 7-year period (2011–2017) who were registered to our hospital—a large, academic pediatric medical center in an urban area with a large referral network—and died before 1 year (365 days) of age, as indicated by a "deceased" status in our electronic medical record (EMR). These deaths may have occurred at our institution or elsewhere. We requested records for all infants from the National Death Index (NDI) per their protocol,[10] including the *ICD-10* code representing the underlying cause of death, record, and entity-axis codes. A list of individuals meeting our criteria was sent to the NDI, and "matches" were returned to us. Each possible match retrieved from the NDI was evaluated and deemed to be a true match if the infant's name, date of birth, date of death (when available), and state in which the death occurred (when available) were consistent with our EMR data. We also reviewed the available medical records of these infants, on whom we have previously published,[7] to identify the proportion with a laboratory-confirmed genetic disorder using our previously described criteria[11] as well as to extract their demographic data and phenotypic features. If a death occurred at our institution, the provider-completed death certificate worksheet was reviewed when available. Clinical data were abstracted from the EMR and entered into an electronic database (REDCap[12]). Most infants were seen at our hospital in an inpatient or outpatient setting (527), although some EMR entries were limited to records review (28) or had no clinical information (18). We included all registered infants to maximize the size of this cohort and included infants who might have been enrolled in our research protocol, through which they had received a diagnosis of a genetic disorder.

Statistical analysis was performed using SPSS version 24 (IBM, Somers, NY), with continuous variables compared using a Mann-Whitney U test for nonparametric data and dichotomous variables compared using a 2-sided Fisher exact test ($P < .05$ considered significant).

RESULTS

Of the 573 deceased infants whom we identified in our EMRs, 517 (90%) were identified in the NDI. Infants not identified in the NDI (56/573) were more likely to have location of death unknown (27/56 [48%] vs 95/517 [18%]; $P < .001$), to have not been seen at our institution (23/56 [41%] vs 23/517 [4%]; $P < .001$), and to have had a younger median age at death (28 days [interquartile range (IQR) 1.5–100.5 days] vs 57 days [IQR 14–162 days]; $P = .005$) when compared with infants whom we successfully identified. Of the infants identified in the NDI, 115 of 517 (22%) had a genetic disorder confirmed by clinical or research laboratory testing (Table 1), and there was no significant difference in the proportion with a confirmed genetic disorder compared with infants not identified in the NDI (11/56 [20%]; $P = .74$). Of the 115 infants with a confirmed genetic disorder, 61 (53%) had an underlying cause of death attributed to *ICD-10* codes Q00-Q99.

We then examined the 47% (54/115) of deceased infants with confirmed genetic disorders who were not coded as Q00-Q99 and identified three main reasons that a code in this category was not reported as the underlying cause of death: (1) the diagnosis was not known before death, (2) the diagnosis was known but not reported as the underlying cause of death, and (3) the diagnosis was known and reported as the underlying cause of death with an *ICD-10* code that was not in the Q00-Q99 category (Figure 1).

The diagnosis was not suspected or known before death in a small number of cases (3/54, 6%). In fact, although molecular diagnoses were identified postmortem in 13 of 54 infants (24%), a genetic disorder was suspected even before molecular confirmation in 10 (77%) of these 13 infants and was therefore included on the death certificate.

For 32 out of 54 infants (59%), the genetic disorder was known but not reflected in national mortality statistics as the underlying cause of death. This discrepancy might have occurred at the provider level. The genetic disorder may not have been noted as the underlying cause of death on the death certificate because it was not thought to have directly caused death or because provider error occurred when completing the death certificate. We were unable to confidently distinguish between purposeful and accidental omissions from EMR data. For example, a patient with Down syndrome may have died as a result of complications associated with a surgical procedure or from aspiration

TABLE 1— Genetic Diagnoses Identified in a Cohort of 517 Infant Deaths: United States, 2011–2018

Syndrome (No.)	*ICD-10* Code
Chromosomal (60)	
Down syndrome (18)	Q90
Edward syndrome (6)	Q91-Q91.3
Patau syndrome (5)	Q91.4-Q91.7
Turner syndrome (2)	Q96
Other trisomies (3)	Q92-Q92.1, Q92.8, Q92.9 Q99, Q99.8, Q99.9
Jacobsen syndrome (3)	None
22q11 deletion syndrome (8)	None
Large chromosomal rearrangements (6) or other deletion/ duplication syndrome (9)	Q92, Q93, Q99
Monogenic (55)	
Other (31)	8/32[a]
Spinal muscular atrophy (9)	G12.9
CHARGE syndrome (3)	None
Autosomal recessive polycystic kidney disease (5)	Q61.1
Smith-Lemli-Opitz syndrome (3)	None
Ornithine transcarbamylase deficiency (2)	E72.4
Nonketotic hyperglycinemia (2)	E72.5

Note. ICD-10 = *International Classification of Diseases, 10th Revision* (Geneva, Switzerland: World Health Organization; 1992). Syndromes appearing more than once are tabulated; all others are grouped together.

[a] 4/8 are Q00-Q99 codes.

pneumonia, and one provider may have felt that those conditions represented death directly caused by Down syndrome whereas another provider did not. A third provider may not have been familiar with completion of death certificates and indicated only "respiratory failure" as the cause of death in either of those scenarios. The discrepancy may also have occurred at the national level, at which a provider may have included the diagnosis of a genetic disorder on the death certificate but chose an alternate condition as the underlying cause of death. Of the 32 infants with genetic disorders but underlying cause-of-death codes reflecting diagnoses that were not genetic (e.g., an infectious process), 23 (72%) had provider-completed death certificates in our EMR, and 15 of 23 certificates (65%) did include the genetic disorder, with 10 of 23 (43%) listing it as the underlying cause—indicating that the NCHS system then selected an alternative underlying cause of death during the coding process. The remaining 5 of 10 certificates listed the genetic disorder as a contributing but not underlying cause.

To investigate one possible explanation for why an infant with a genetic disorder might be coded with a "nongenetic" underlying cause of death, we evaluated for a difference in median age at death between infants with genetic disorders who were coded as Q00-Q99 versus infants not coded as Q00-Q99, and we did not find a significant difference (median 64 days, IQR 29–170 days vs median 122 days, IQR 30.75–178.5 days; $P = .35$). This finding suggested that older infants, who might have acquired medical issues secondary to or distinct from the genetic disorder, were not more likely to be coded with a cause of death outside of the Q00-Q99 category. Misreporting as a result of diagnoses being known, but not captured in the NDI as the underlying cause of death, also may have been attributed to problems at the coding level if the genetic disorder was included on the death certificate but not extracted by the NCHS system as the underlying cause. Of all infants with confirmed genetic disorders, 75 of 115 (65%) had a Q00-Q99 code listed in the entity or record axis data. Therefore, in 14 infants, a diagnosis in this category was on the death certificate but was not selected as the underlying cause of death by the NDI's classification system.

For the remaining 19 of 54 infants (35%), the diagnosis of a genetic disorder was made either clinically or molecularly and was reported as the underlying cause of death but was not captured in the Q00-Q99 category. This was caused by the design of the *ICD-10* classification system whereby genetic disorders without congenital anomalies are often reported in an organ system–based category instead. For example, spinal muscular atrophy (G12.9) and other genetic neuromuscular diseases are coded under diseases of the nervous system (G00-G98), and metabolic disorders (e.g., urea cycle disorders, E72.2) are coded under endocrine, nutritional, and metabolic diseases (E00-E88). Most monogenic disorders diagnosed in the infants in our cohort did not have a distinct *ICD-10* code, and most of the codes that did exist were predominantly not in the Q00-Q99 category (Table 1).

Overall, we found that infants with diagnoses of genetic disorders that were

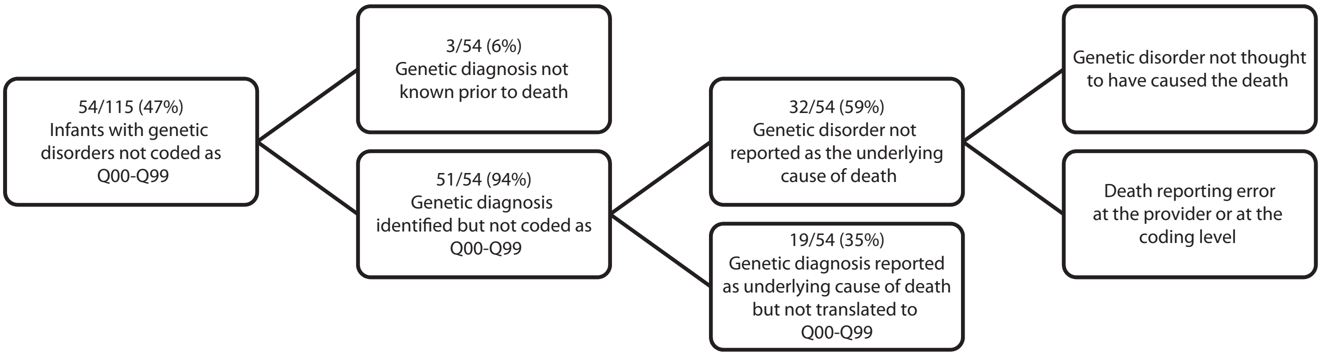

FIGURE 1— **Possible Explanations for Infants With Genetic Disorders Not Being Coded as *ICD-10* Q00-Q99: United States, 2011–2018**

Note. ICD-10 = *International Classification of Diseases, 10th Revision* (Geneva, Switzerland: World Health Organization; 1992).

coded as Q00-Q99 for the underlying cause of death were more likely to have chromosomal disorders (such as Down syndrome or other aneuploidy syndromes), whereas infants with diagnoses that were not coded as Q00-Q99 were more likely to have monogenic disorders (Table 2). Additionally, we found that of the 402 infants without a confirmed genetic disorder, 192 (48%) were categorized under the Q00-Q99 code for the underlying cause of death, reflecting deaths attributable to congenital anomalies that may or may not have an underlying Mendelian genetic etiology. The deaths of nearly half of the infants in our overall cohort (253/517, 49%) were attributed to a Q00-Q99 code, most often congenital anomalies of the heart or circulatory system (167/253, 66%); congenital diaphragmatic hernia, exomphalos, gastroschisis, and other malformations of the musculoskeletal system or integument (30/253, 12%); or chromosomal abnormalities (20/253, 8%). A minority of these infants with deaths caused by congenital anomalies had a confirmed molecular genetic disorder (61/253, 24%) that we ascertained from the records available, although a proportion may have had disorders that either were not identified because of lack of testing or were identified but not available to us in the EMR. Additional features of the infants with or without underlying cause of death codes in the Q00-Q99 category, such as sex and history of preterm birth, are presented in Table 2.

DISCUSSION

Our data demonstrated that genetic disorders, although a leading cause of infant mortality, are not accurately captured by national mortality statistics, as reflected in the 54 of 117 infants with genetic disorders whose underlying cause of death was not reported in the Q00-Q99 category that is commonly used to represent genetic conditions. This inaccuracy is a particular issue for monogenic conditions, many of which either do not have a unique *ICD-10* code or have one but are reported within an organ system–based category. It reflects the design of the *ICD-10* coding system, which groups infants who have common chromosomal abnormalities with infants who have structural malformations in the same Q00-Q99 category. Our data also showed that many Mendelian disorders either do not cause birth defects or are not properly translated from the death report description to an *ICD-10* code reflecting the genetic disorder. Indeed, few Mendelian genetic conditions have a distinct *ICD-10* code, and it would be difficult for any system to correctly classify the many eponymous disorders causing congenital anomalies into the Q00-Q99 category. Thus, a certain proportion of diagnoses within each *ICD-10* organ system category actually represents genetic disorders. Categories that seem particularly enriched for Mendelian genetic disorders are diseases of the nervous system (G00-G98) and endocrine, nutritional, and metabolic diseases (E00-E88). Conversely, even within the Q00-Q99 category, not all conditions are genetic because certain congenital anomalies may arise as a result of teratogenic exposure (e.g., diabetic embryopathy or fetal hydantoin syndrome) or deformations or disruptions (e.g., amniotic band sequence). The scope of the total contribution of Mendelian genetic disorders, combined across all categories, to infant mortality is therefore unclear with current reporting techniques.

Further insight into this scope is important because the identification of a Mendelian genetic disorder may suggest interventions at the individual or

TABLE 2— Comparison of Demographic and Clinical Features Between Infants With and Without an Underlying Cause of Death in the *ICD-10* Q00-Q99 Category: United States, 2011–2018

Infant Demographic	Underlying Cause-of-Death Code		*P*	
	Q00-Q99, No./Total No. (%) or Median (IQR)	Not Q00-Q99, No./Total No. (%) or Median (IQR)		Total, No./Total No. (%) or Median (IQR)
Sex			.42	
Female	111/253 (44)	106/264 (40)		217/517 (42)
Male	142/253 (56)	160/264 (60)		302/517 (58)
History of preterm delivery			< .001	
Yes	86/239 (36)	133/254 (52)		219/517 (42)
No	153/239 (64)	121/254 (48)		274/517 (53)
Unknown	14/517	10/517		24/517 (5)
Age at death, days	57(15–163.5)	56.5 (13–162)	.88	57 (14–162)
Genetic diagnosis	61/253 (24)	54/253 (21)	.34	115/517 (22)
Chromosomal	43/61 (70)	17/54 (31)	< .001	60/115 (52)
Monogenic	18/61 (30)	37/54 (69)	< .001	55/115 (48)

Note. ICD-10 = *International Classification of Diseases, 10th Revision* (Geneva, Switzerland: World Health Organization; 1992); IQR = interquartile range. "Q00-Q99" refers to infant deaths classified with *ICD-10* codes Q00-Q99 as the underlying cause of death, whereas "Not Q00-Q99" refers to infant deaths classified with other *ICD-10* codes as the underlying cause of death.

broader public health level. Multiple previous studies have demonstrated that genetic syndromes, whether monogenic or chromosomal, underlie a substantial proportion of stillbirths[13] and infant deaths.[7,11,14,15] A recent publication of a large cohort of infants diagnosed by exome sequencing demonstrated that infants with diagnoses of genetic disorders were more likely to die in the first 120 days of life than infants without, and nearly half of all infant deaths in that study occurred in the setting of a confirmed molecular disorder.[6] We also previously demonstrated that genetic disorders affect a substantial proportion of infants admitted to our neonatal intensive care unit who die in early childhood[11] and suggested inaccuracies in death reporting in this population.[7] Death certificates for neonates and infants are known to be highly inaccurate, with previous studies revealing discordance between information reported on the death certificate compared with medical records[16] or autopsy results.[17]

This study provided further support for the inaccuracy of infant mortality data and expanded on our previous work by analyzing the consequences of delayed diagnoses and inaccurate completion of the death certificate,[7,11] as reflected in the high proportion of infants with genetic disorders that were not reported as such after death. Our genotype and phenotype data permitted an evaluation of why this occurs and we found that, most often, the explanation related to either inaccurate death reporting, which may be modifiable,[18,19] or shortfalls of the current coding system, which are more difficult to modify.[9,20] For similar reasons, other conditions are also underrepresented or misrepresented in mortality statistics. For example, epilepsy has been shown to be underreported on death certificates and was identified as an underlying or contributing cause for only 7% of individuals known to have epilepsy in a large clinical cohort.[21]

The contribution of prematurity to infant mortality has also been shown to be underreported,[20] which also may occur either at the provider level or at the coding level.[8,22,23] The prematurity experience is particularly informative because it has shown that attributing deaths to organ system–based diagnoses suggests that strategies to reduce infant deaths ideally would be developed to treat these failing organs rather than prevent the root cause, such as preterm birth or low birth weight[20,24] or—as we would argue—monogenic Mendelian disorders. Indeed, preterm birth was previously suggested as the leading cause of infant mortality in the United States if all prematurity-related causes were combined,[20] and a modified classification scheme has been proposed (Dollfus et al.,[24] updated in 2015 by Nakamura et al.[25]) to understand infant mortality, taking this proposed scheme into account. It is unclear how the contribution of prematurity, top-ranked by the Dollfus classification system, would compare with deaths caused by genetic disorders if all genetic disorders were appropriately characterized in a cohesive group because these deaths face a similar categorization challenge when distributed by organ system. Further updates to the Dollfus classification scheme might take this consideration into account, particularly because the genetic basis for many congenital disorders is understood or will be understood because of advances in genomic technology.

Our results and those of others[9,26] also reveal the limitations of using *ICD-9* or *-10* data to study the prevalence of either genetic disorders or congenital anomalies related to mortality or other outcomes. For rare diseases, however, this remains one of the only options, with enrollment in registries, surveillance programs, and natural history studies representing another approach.[9,26] The use of billing or cause-of-death codes in a large, electronic data set, as has been done in other studies,[27] compared with the use of data acquired through programs such as the National Birth Defects Surveillance Study[28] illustrates a trade-off between strength in numbers (from population databases) and increased accuracy in genotyping and phenotyping (from surveillance programs with active case-finding and confirmation), and the method that we used for the current study is less feasible at scale. Nevertheless, improvements to the *ICD* coding system are needed to more accurately track outcomes related to these conditions, and other methods to acquire these data should be explored. The lack of ability to distinguish between genetic and teratogenic causes of birth defects was described many years ago with relation to *ICD-9*, which highlighted the need for dedicated codes for particular genetic syndromes.[9] Although the number of codes related to congenital anomalies increased with *ICD-10*, the ability to distinguish genetic from teratogenic causes of congenital anomalies was not addressed.[9] The introduction of *ICD-11* represents another opportunity to incorporate genomic knowledge into public health databases.

LIMITATIONS

Limitations to this study included the nature of our pediatric hospital, which is not a birth hospital; thus, our population is enriched for older infants with congenital anomalies or other subspecialty-based concerns who have survived long enough to be transferred. This likely also impacted our ability to identify deceased infants in the NDI because some deaths may have occurred outside the United States if an infant was transferred home for palliative care or if an infant's name was changed from the name assigned at the birth hospital without our medical record system being updated. Additionally, we relied on the information available to us via our research study or the EMR to determine the proportion of infants with genetic diagnoses, so additional infants may have had diagnoses of which we were not aware. This was also a single institution study, and although our institution is a large, academic hospital that receives many national and international referrals for specialty care, this cohort primarily represented infants from our catchment area. However, although the etiologic landscape of infant deaths in other regions may differ, particularly related to use of pregnancy-terminating procedures,[29] the underlying reporting and coding issues should be similar. Finally, relying on "deceased" status in our EMR may not have captured all deaths, particularly infants who died outside of our institution, because we may not have been notified of all deaths.

PUBLIC HEALTH IMPLICATIONS

Current understanding of the impact of inaccurate death reporting on mortality statistics is incomplete,[30] and further efforts should be made to address this knowledge deficit. It would require not only improved reporting of deaths and possible further updating of the Dollfus classification scheme to include all Mendelian genetic disorders in one category but also expanded access to genetic testing to identify the mortality burden of rare genetic conditions. These results have important implications. Because the decision of whether to offer treatment to a critically ill infant, continue life-sustaining measures, or continue a pregnancy in the case of a confirmed genetic disorder may hinge on the chances of survival—for example, extracorporeal membrane oxygenation is not routinely offered for infants with "lethal" genetic conditions such as Trisomy 13 or 18[31]—accurate mortality statistics are necessary to guide these decisions. Additionally, public health resources, particularly funding to drive innovative research, are often allocated using published mortality rates to address conditions with the highest public health impact. Accurate classification of infant deaths has been recognized as a critical component of prevention efforts.[22] Thus, attempts to mitigate the leading cause of infant mortality depend on producing higher quality data to augment our understanding of these diseases and their mortality burden. AJPH

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CONTRIBUTORS

W.-H. Tan and P. B. Agrawal were co-senior authors. M. H. Wojcik conceptualized and designed the study, analyzed the data, and wrote the initial manuscript draft. R. Stadelmaier contributed to data acquisition and analysis and critically revised the manuscript for intellectual content. D. Heinke contributed to data analysis and critically revised the manuscript for intellectual content. I. A. Holm, W.-H. Tan, and P. B. Agrawal contributed to study design and conceptualization and critically revised the manuscript for intellectual content.

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CONFLICTS OF INTEREST

The authors have no conflicts of interest to disclose.

HUMAN PARTICIPANT PROTECTION

This study was approved by the institutional review board of Boston Children's Hospital as a retrospective study with a waiver of informed consent because of the nature of the study. Infants diagnosed via research testing were enrolled in a separate institutional review board–approved study at Boston Children's Hospital.

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