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/2RESAgu). As has also been noted (https://bit.ly/2RESAgu), 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/2whXuc). 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/2Tc24g). 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/2RESAgu).

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DOI: https://doi.org/10.2105/AJPH.2021.306440

ACKNOWLEDGMENTS

Support for this work was provided by the National Institute of Minority Health Disparities (grant MD 006923) and the National Institute of Mental Health (grant MH 115344).