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’ 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 (Soto 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; Benson, 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 Ettenman, 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.

Soto 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.

**CONTRIBUTORS**
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