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Dead Wrong: The Growing List of Racial/Ethnic Disparities in Childhood Mortality

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“When our children die, we drop them into the unknown, shuddering with fear. We know that they go out from us, and we stand, and pity, and wonder.”

—Henry Ward Beecher, American clergyman, abolitionist, and author; four of his eight children died in childhood.

Marked, disturbing racial/ethnic disparities exist in childhood and adolescent deaths, and these disparities have persisted over many decades.¹ For example, over a 43-year period, overall mortality rates have been consistently higher for African-American (AA) children, compared with white children, with twice the mortality rate for AA children among those 1–4 years old, and an increase in the mortality disparity ratio in the most recent 10-year period examined.² AA children are seven times more likely than white children to die from asthma, and this disparity has increased 40% from 2001 to 2010.³ Although the overall infant mortality rate in the US continues to fall, AAs continue to have the highest infant mortality rate, at double that of whites, and the disparity ratio has not changed over time.⁴ AA children and young adults are significantly more likely than white children to die by drowning, including approximately six times the childhood death rate for drowning in swimming pools.⁵ AA children are more than four times likely to die after a liver transplant,⁶ have about twice the hazards of dying of acute lymphoblastic leukemia (ALL),^{7,8} and among those with Down Syndrome, AAs have twice the adjusted hazards of death across almost all age groups (including significant higher mortality in infants 2–12 months old)⁹ and a substantially lower median age at death (25 years old vs. 50 in whites).¹⁰

Latino children are significantly more likely than white children to die from cancer overall, and from Ewing sarcoma, leukemias, central nervous system tumors, and melanoma, including a 37% lower five-year survival rate for Ewing sarcoma.¹¹ Latino children have about double the adjusted hazards of death vs. white children among those with ALL⁷ and Wilms' tumor.¹² Latino children are significantly more likely than white children to die from drowning in neighborhood pools (defined as community-shared apartment and housing-complex pools).¹³ Puerto Rican children have four times the hazards of dying from

ALL as white children (and the highest mortality rate of any racial/ethnic group or subgroup),^{7,8} and among 1–4 year-old children, Central and South Americans and Puerto Ricans have significantly higher overall crude death rates.²

Although fewer studies have been conducted on mortality disparities for American Indian/Alaska Native (AIAN) and Asian/Pacific Islander (API) children, the documented disparities are just as stark. AIAN children are two to three times more likely (depending on the age group) to die than white children.¹⁴ AIAN newborns and infants are significantly more likely than their white counterparts to die from congenital malformations, SIDS, and sepsis, and AIAN children 1–19 years old have a significantly higher relative risk of death from unintentional injuries, homicide, influenza, and pneumonia.^{14,15} AIAN children have twice the adjusted hazards of white children of dying from ALL and from neuroblastoma.^{7,8,16} Hawaiian children have a significantly higher risk of death overall than white children,² and Asian children (but not Pacific Islander children) have significantly higher hazards of dying from ALL than white children.⁷

In this issue of *The Journal*, two articles add to the growing, lengthy roster of racial/ethnic disparities in childhood and adolescent mortality.^{17,18} Wang et al. analyzed nine years of pooled data on 21 birth defects from 12 population-based birth-defects surveillance programs from across the country.¹⁷ This data set includes 98,833 children with at least one of the 21 birth defects, drawn from 14 million live births, thereby representing the largest population-based cohort of US infants with birth defects for whom survival up to eight years old can be evaluated. The study documents racial/ethnic mortality disparities for all age groups examined, including significantly higher eight-year adjusted hazards of death for 12 of 21 defects for AA children, eight defects for Latino children, four defects for API children, and one defect for AIAN children. Some of the disparities (compared with white children) in eight-year outcomes were striking: an encephalocele mortality rate of 70% for AIAN children vs. 27% for white children; triple the adjusted hazards of death for AIAN and API children with encephalocele; and double the adjusted hazards of death for AA children with esophageal atresia/tracheoesophageal fistula, Latino children with common truncus, and API children with atrioventricular septal defects. These findings complement the results of several recent studies of single state registries which documented significantly higher adjusted hazards (compared with white children) of early childhood death for AAs and Latinos with major birth defects overall¹⁹ and with several specific congenital heart defects.^{20,21,22}

In the second study in this issue of *The Journal*, Chan et al. conducted an analysis of three years of the nationally representative Kids' Inpatient Database to examine 38,801 children undergoing congenital heart surgery.¹⁸ After adjusting for a wide variety of potential confounders, AA children and those of "other" race/ethnicity (including AIAN and any race/ethnicity besides white, Latino, or API) had significantly higher odds than their white counterparts of overall in-hospital mortality and failure-to-rescue (mortality after experiencing an inpatient complication). These findings complement prior studies which found significantly higher adjusted odds of in-hospital mortality (compared with white children) after congenital heart surgery for either AA children alone,^{23,24} or both AA and Latino children.^{25,26,27}

There is an urgent need to understand and eliminate racial/ethnic disparities in childhood mortality, not only because such glaring inequities cannot be tolerated, but also because our nation is growing increasingly diverse, so allowing such mortality disparities to persist will mean greater numbers of minority children and US children will die with each passing year. Racial/ethnic minority children currently comprise 48% of US children.²⁸ US Census projections indicate minority children will outnumber white children in the US in three years, and by 2060, over two-thirds of our nation's children will be minority.²⁹ In 2011, for the first time in our nation's history, minority births outnumbered white births,³⁰ and minorities comprised the majority of children younger than one year old.³¹

Why are there such dramatic racial/ethnic disparities in childhood mortality? In many cases, the reasons are unclear, highlighting the need for much more research on identifying root causes. There are, however, several promising areas which merit further investigation and have the potential to reduce or eliminate disparities. First, for certain conditions, genetic differences may underlie racial/ethnic mortality disparities, presenting opportunities to eliminate disparities by better tailoring therapies. A recent study revealed that the proportion of Native American genetic ancestry was significantly associated with risk of relapse in children with ALL across racial/ethnic groups, including whites, even after adjusting for known prognostic factors.³² Furthermore, these ancestry-related differences in ALL relapse risk were eliminated by adding a single extra phase of chemotherapy, suggesting that tailoring therapy can overcome the ancestry-related risk of relapse.³² Second, delays in diagnosis and treatment can result in untreated conditions, disease progression, presentation at higher-risk disease stages, and accessing less effective treatment early in the course of a disease. Research documents, for example, that AA children receive their diagnosis of autism a mean of 1.4 years later than white children, and are in mental-health treatment an average of 13 months longer than white children before receiving the autism diagnosis.³³ Third, it has been shown that children who need specialty care and receive that care from specialists have significantly fewer hospitalizations and emergency-department visits and a higher likelihood of care consistent with national practice guidelines, compared with children who need but do not receive specialty care.^{34,35} Nevertheless, minority children are significantly more likely than white children to have problems obtaining specialty care, a barrier which has actually worsened over time.³⁶ Fourth, although culturally competent care has been shown to improve the quality of care for minority children,³⁷ it is not clear that minority children consistently receive culturally competent care. Finally, both conscious and unconscious bias occur in healthcare systems and the decision-making processes of some clinicians.³⁸ For example, although survival for children with end-stage renal disease is known to be significantly higher for those receiving preemptive renal transplantation vs. hemodialysis as their initial treatment, AA children are three times less likely and Latino children two times less likely than white children to receive living-donor preemptive kidney transplants, after adjustment for relevant confounders, and regardless of insurance coverage.³⁹

Several steps must be taken to eliminate racial/ethnic disparities in childhood deaths: 1) racial/ethnic data (via parental self-identification) routinely must be collected on all pediatric patients, so that mortality disparities can be identified, tracked, targeted as part of quality-improvement efforts, and publicly reported on a regular basis, consistent with recent

Institute of Medicine reports^{40,41} and the Patient Protection and Affordable Care Act; 2) more research is needed on the root causes of mortality disparities, particularly regarding differential genetic and ancestry-related risks, diagnostic and treatment delays, access barriers to specialty care, the cultural competency of pediatric care, and conscious and unconscious bias in healthcare systems and clinical decision-making; and 3) patient-centered interventions targeting the elimination of mortality disparities need to be developed, funded, implemented, and evaluated, given that such interventions have been shown to eliminate other disparities for minority children and to save money.^{42,43}

In 1966, Martin Luther King, Jr., stated, “Of all the forms of inequality, injustice in health care is the most shocking and inhuman.” The medical literature and the two new studies in this issue of *The Journal* document that dramatic and alarming racial/ethnic disparities exist in childhood and adolescent deaths, and these disparities have persisted over many decades. Urgent action is needed, as no child should ever be at greater risk of dying simply because of his or her race/ethnicity.

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