

Dying young

Eliminating racial disparities in neuromuscular disease outcomes

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Decades of research show that racial and ethnic minority patients have worse access to health care and inferior clinical outcomes than white patients.^{1,2} Life expectancy for all racial groups continues to improve in the United States, yet remains about 5 years less for black than white patients, primarily because of black patients' higher rate of heart disease.³ The racial disparity is not limited to cardiac conditions—the same inequity exists for neurologic conditions. Black patients die younger than white patients from cerebrovascular disease; have less access to Parkinson disease treatments, such as dopaminergic medications or deep brain stimulation; are less likely to receive acute interventions like tissue plasminogen activator for ischemic stroke; and are referred less often for subspecialty evaluations.⁴⁻⁸ Black-white disparities are now evident for patients with muscular dystrophy (MD), a group of inherited muscle diseases that lead to early death due to respiratory or cardiac failure.

In this issue of *Neurology*®, Kenneson et al.⁹ deepen our view of racial inequities in neurologic care and outcomes by reporting strikingly early mortality for black patients with MD. The authors examined 20 years of US mortality data and found that black patients with MD die 10 to 12 years younger than their white counterparts—this gap in age at death is among the largest ever demonstrated.^{3,9} Furthermore, white patients with MD enjoy increasing survival, while survival of black patients with MD barely budes. The authors identify black-white differences in site of death that suggest poorer planning of care for black patients with MD: white patients are more likely to die at home or long-term care facilities or hospice, while black patients tend to die in, or en route to, acute hospitals or emergency rooms.

The described black-white inequities in MD outcomes occurred during decades of small but steady MD therapeutic advances.^{10,11} All patients with MD face incurable disease, yet many live longer because of innovations such as mechanically assisted cough

and ventilation devices or through early detection and treatment of cardiomyopathy and cardiac arrhythmias. Ambulation and life spans of patients with Duchenne MD are prolonged by glucocorticoids slowing the progression of muscle weakness, scoliosis, and pulmonary compromise.

What explains the racial chasm in survival for patients with inherited neurologic disease? While racial differences in the prevalence and natural history of different MD types could conceivably account for the observed disparities, such racial patterns have not been documented.¹² Black race could be a proxy for different cultural beliefs or social support systems that may compromise neurologic outcomes.^{6,13} It is also possible that MD acts synergistically with known racial disparities in comorbidities or epigenetic factors such as environmental exposure to toxins.^{6,13} It is plausible that racial disparities in education compromise black patients' understanding of neurologic disease and treatment options, interfering with their seeking appropriate care.^{4,14}

Inequities in the health delivery system—and the multiple ways in which race constrains access to care—seem the most likely explanation for the observed MD black-white mortality gap.^{1,13,15} Black patients receive worse care than white patients for 50% of core quality measures, and enjoy better care than white patients for only 15% of core measures.² Racial and ethnic minorities receive care disproportionately in lower-performing institutions, and may encounter greater geographic barriers to advanced treatments like deep brain stimulation, or even more routine treatments such as tissue plasminogen activator.^{1,15,e1} The black-white gap in insurance coverage is shrinking; however, nonelderly black patients remain 1.5 times more likely than white patients to lack any type of insurance and about twice as likely to rely on Medicaid.^{e2} Medicaid compares favorably with private insurance in providing access to primary care, but does not provide comparable access to specialty care.^{e3} Uninsured and Medicaid

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patients are less likely than privately insured patients to receive standard-of-care treatments such as abortive or prophylactic migraine medications, and are less likely to undergo expensive interventions like temporal lobe surgery for treatment of epilepsy.^{e4,e5} This is particularly worrisome because more than half of the new health coverage under the 2010 National Health Reform will be Medicaid.

The data of Kenneson et al.⁹ challenge neurologists to study and address differences in outcome and care not explained on clinical grounds. Their excellent study is unfortunately constrained by its reliance on death certificates, which lack clinical and socioeconomic detail and may inaccurately report cause of death and race/ethnicity.^{e1,e6} Furthermore, while the authors examine a heterogeneous group of neuromuscular diseases, the high death rates in younger males suggest that their results may be driven by outcomes in patients with Duchenne MD. Moreover, we know nothing about MD patients' function and quality of life, which they may value as highly as life extension.

Science holds out great hope for patients with MD. We anticipate improvement in the survival of patients with MD with expanding knowledge of MD genetics and the advent of genetic therapies. However, Kenneson et al. remind us that we must work just as hard to minimize social barriers and provide excellent neurologic care to all patients.^{e7-e9} In neurology, we labor to save lives and preserve our patients' thinking, speech, and movement—the very essence of what it means to be human. Equitable access to neurologic care is a clinical and humanitarian imperative.

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