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Dying Poor in the US—Disparities in End-of-Life Care

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The coronavirus disease 2019 (COVID-19) pandemic has focused attention on stark disparities in the US, with higher rates of infections and deaths among lower-income populations and communities of color. Illness and death rates are not the only sources of health inequity in this country. There are also substantial differences in the care that patients with serious illnesses receive near the end of life that are based on race or socioeconomic status. Although pandemic-related efforts to improve equity rightfully focus on preventing death, in this and numerous other contexts, policy makers and clinicians should also work to eliminate disparities in end-of-life care.

Multiple dimensions of end-of-life care vary by socioeconomic status and race. Medicare and Medicaid are key players in end-of-life care for low-income populations. All told, more than 2 million Medicare beneficiaries die annually, representing roughly 80% of deaths in the US, with about half enrolled in hospice at the time of death. Comparable statistics are not available for Medicaid because insurance among decedents is not consistently documented outside Medicare (even though 20% of Medicare beneficiaries are dually enrolled in Medicaid overall). Broadly speaking, the 2 programs cover hospice in much the same way: patients can elect hospice if they have a condition with a limited life expectancy (it is ≤6 months for Medicare and it varies by state for Medicaid). Hospice programs are paid a daily rate and are responsible for all services related to the patient’s hospice diagnosis, including medications and care from nurses, social workers, and chaplains. For both Medicare and Medicaid, electing hospice generally requires forgoing curative treatments (Medicaid patients aged <21 years are an exception and can continue such treatments).

One important difference between Medicare and Medicaid hospice is payment for nursing facility care. Other than hospice general inpatient care, which accounts for just 1.5% of Medicare hospice days, Medicare does not generally pay for custodial care, such as feeding or toileting assistance. In contrast, Medicaid is the nation’s largest payer for long-term care, funding more than half of all nursing home spending.

Although all Medicare beneficiaries can access the hospice benefit, for Medicaid, states can choose whether to include a hospice benefit at all. Even though most states cover hospice, several limit benefits to specific subpopulations in Medicaid, and others do not cover hospice or have eliminated hospice benefits in the past for budgetary reasons. Some states also limit the number of prescriptions that Medicaid patients can receive, which can impair clinicians’ ability to manage pain and other distressing symptoms. In addition, as laid bare during the pandemic, Medicaid chronically underfunds nursing home care, producing a crisis in quality, particularly in facilities primarily serving Black patients.

Other groups of seriously ill patients are ineligible for federally subsidized insurance. One such group includes the 2 to 3 million adults with low income in states that did not expand Medicaid. Another group includes undocumented immigrants, for whom the lack of insurance options, combined with cultural and language barriers, creates substantial barriers to end-of-life care. Nationally, 1 of 3 hospice programs limit or refuse to treat this population. Undocumented immigrants are also more likely to receive intermittent emergency care rather than the longitudinal care necessary for advanced care planning and good symptom management.

For different reasons, hospice and palliative care are also often inaccessible for American Indians/Alaska Natives. Poverty and geographical isolation are key contributors to poor access to end-of-life care services in tribal communities; this resembles broader disparities for rural patients of all races. Many tribal health organizations are also unable to satisfy the myriad Medicare and Medicaid requirements to provide hospice services, leaving patients reliant on outside hospice programs that frequently are insensitive to tribal culture and practices regarding end-of-life care.

Beyond hospice, disparities also exist with respect to palliative care services. Palliative care, which can be provided to patients at all stages of serious illness (without the 6-month life expectancy requirement for hospice), can improve patient quality of life, symptom burden, and patient and caregiver satisfaction and can also lower health care use. Yet a recent study found that patients with metastatic cancer at primarily minority-serving hospitals were
33% less likely to receive palliative care than those in alternative hospitals, and other studies show similar racial disparities.

Most concerning, research demonstrates that these differences in access to hospice and palliative care manifest in adverse experiences (such as more pain; greater financial distress; greater caregiver burden, especially among women; and ultimately worse family-reported experiences with death) for lower-income populations and racial/ethnic minorities with serious advanced illnesses. Another contributor to this pattern is that hospice and palliative care have traditionally focused on cancer, whereas other illnesses such as end-stage kidney disease—with substantially higher rates among racial minorities—can produce symptoms as severe as those of cancer, but patients with these conditions are less likely to receive key elements of high-quality end-of-life care.

What can be done? First, financial access to care must be improved. Congress should reclassify hospice as an essential benefit required in state Medicaid programs, and states should eliminate prescription drug caps that impair adequate end-of-life symptom management. A pathway to affordable coverage for undocumented immigrants to provide access to meaningful health care throughout the life cycle is also critical.

Second, Medicaid’s long-term care role—in contrast to Medicare—holds out the potential for expanding access to inpatient hospice, a setting with better family-reported quality of end-of-life care than that provided by hospitals and nursing homes. Since lack of adequate support at home is a major barrier for many families considering hospice, Medicaid could potentially facilitate hospice use to a greater extent than other programs because of its long-term care dimension. But this would require adequate funding to ensure quality and improved hospice coverage in Medicaid. One potential model is the Veterans Health Administration, which has made substantial investments in palliative and end-of-life care across inpatient, outpatient, and long-term care settings.

Third, efforts to expand the availability of hospice and palliative care in underserved hospitals and communities are critical. The COVID-19 pandemic, with its rapid deployment of telemedicine, suggests a new pathway for bringing palliative care specialists to rural areas. In addition, proposed legislation would facilitate hospice provision through rural health clinics and federally qualified health centers, which currently are prohibited from participating in the Medicare hospice benefit.

Policy makers and clinicians should expand the lens of health equity to consider not just disparities in disease prevention, treatment, and life expectancy, but also disparities in the quality of end-of-life care. A “good death” should be a priority for all seriously ill patients, regardless of race, immigration status, or income. •

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