Racial and Ethnic Disparities in Dementia Care
Next Steps

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Lin and colleagues examine how the use and cost of hospice and hospital services received at the end of life differ by race and ethnicity within a dementia cohort. They find that non-Hispanic Black and Hispanic decedents with dementia were less likely to have advance care planning than their non-Hispanic White counterparts. Likely relatedly, non-Hispanic Black and Hispanic decedents with dementia were much less likely to use hospice services and more likely to use hospital and emergency department services at the end of life, even among those who did enter hospice care.

For patients living with dementia from diverse racial and ethnic backgrounds, this represents one of many differences in dementia and dementia-related care. It is well-documented that Black and Hispanic individuals have higher risk of dementia that is not fully accounted for by genetics alone. Despite the higher risk and prevalence, racial and ethnic minority populations are less likely to be formally diagnosed with dementia and more often diagnosed at later stages of the disease. After diagnosis, racial and ethnic differences in care patterns continue, with Black and Hispanic patients living with dementia being more likely to rely on family caregivers and less likely to use nursing homes than their White counterparts. This study by Lin adds another dimension to our understanding of the health care utilization differences among dementia patients at the end of life.

First, let us place these findings in the broader context of end-of-life care. Racial differences in end-of-life care are not unique to a dementia cohort. Despite the growth of hospice care in the US, Black decedents receive more aggressive care, have higher end-of-life health care spending, and are less likely to use hospice services than White decedents. Several reasons have been hypothesized, including patient preferences for more aggressive care, history of distrust in the health care system, lack of in-home resources to fully support care at home, miscommunication and misunderstanding of treatment options, and fewer conversations around advanced care planning. We need to more completely understand the structural and patient-level drivers underlying these differences to know whether it is even beneficial to address differences in end-of-life health care utilization. For example, if Black and Hispanic patients prefer all interventions at the end of life, then not having advance care planning documents, while perhaps not optimal, may allow patients to receive their preferred level of care and avoid miscommunication with doctors and staff. If lower levels of hospice use and higher levels of care received in acute care settings are based on patient preferences, then policies need to match treatment to patient preferences, perhaps allowing these differences to continue, and perhaps even to expand in order to best support patients and their families during the end of life. This is not an easy task, but one clinicians and researchers face daily and something that should be considered carefully when situating these findings in the broader context of end-of-life care.

Without digging deeper into the preferences and contextual factors behind these utilization differences, it is difficult to know how to interpret some of these findings, and what steps to take to promote or eliminate them. For example, Lin and colleagues’ findings that hospital and emergency department use is higher among non-Hispanic Black and Hispanic decedents, even after entering hospice, could indicate that the quality of accessible hospice services is low, and so they are unable to continue to serve their patients adequately without hospital resources. However, it could also mean that patient preferences for acute care are strong enough that they get their desired level of acute care, even in hospice. If these differential patterns are based on factors other than patient preferences, such as distrust of the health care system, differential access to (high-quality) hospice services...
care, incomplete or incorrect knowledge of hospice care, or less engagement in advance care planning; then this is not just a difference in utilization patterns based on preferences, but a true disparity that should be addressed.

Finally, we should be clear that the end goal is for health equity, not necessarily health care utilization equality. Indeed, health care can do more to address the structural and patient-level factors that contribute to both lower health and higher health care utilization among non-Hispanic Black and Hispanic patients living with dementia. Striving to address the societal issues created because of structural racism is thus an imperative to achieve this goal. However, higher health care utilization is not always, or even necessarily, equal to inequitable care.

It is important to emphasize that the previously documented disparities in dementia care occur early, are complex, and continue throughout multiple aspects of patient care; racial and ethnic differences at end of life should therefore not be the only focus in advancing equity in dementia. Instead, we can utilize the findings from Lin and colleagues to understand the policies and interventions necessary to determine the underlying factors that may influence utilization and treatment preferences among patients with dementia, especially during end of life.

ARTICLE INFORMATION
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REFERENCES


