

## Letter to the Editor

### ***Inequities in End-of-Life Care Among Immigrant Patients Exaggerated by the COVID-19 Pandemic***



Although death has been called the great equalizer, not all deaths are equal. This appears to be particularly true for U.S. immigrants. The COVID-19 pandemic has revealed the dramatic inequities in end-of-life care that exist among immigrants. While racial and ethnic disparities in COVID-19 infection and mortality rates have been highlighted recently,<sup>1</sup> little attention is paid to COVID-19's effects on U.S. immigrants. There is a need for greater awareness that immigrant patients are dying cruel, unfair deaths with little focus on actionable change to reduce suffering among this largely underserved population.

Optimal end-of-life care—which prioritizes reducing patients' suffering and easing the transition from life to death—has become an increasing national public health concern.<sup>2</sup> But often brutal circumstances of U.S. immigrants' deaths amid the COVID-19 pandemic remain largely ignored. While the current administration offers hope of mitigation of mistreatment imposed by the former administration, the ravages of the COVID-19 pandemic have proven particularly punishing to dying immigrant patients and their surviving family members.

Heartbreaking conditions around death and dying due to COVID-19 illuminate the pre-existing fractures in our healthcare system that leave immigrants exposed. For instance, immigrants are nearly twice as likely as non-immigrants to receive extremely burdensome, unbeneficial aggressive care in their final weeks of life including mechanical ventilation, cardiopulmonary resuscitation, and feeding tubes.<sup>3</sup> Most alarming, immigrants are more than twice as likely as non-immigrant patients to receive such aggressive care, which our data suggest is counter to their own values and preferences.<sup>3</sup> This stark disparity is likely the result of a variety of factors, including a medical default mode of doing everything possible to keep patients alive even

when the ultimate outcome is suffering a painful death. Other factors undermining optimal end-of-life care for immigrant patients include linguistic challenges, lack of health literacy and health advocacy, financial hardship, perceived medical mistrust and concerns about discrimination such as the perception that they are being denied the level or quality of care that US citizens would receive.<sup>4</sup>

To make matters worse, immigrants are dying alone and at higher rates than non-immigrants due to COVID-19. Traditionally, the default mode of the healthcare system is full tilt for applying any and all care needed to keep the patient alive. Our own work demonstrates that immigrant cancer patients experience worse quality of death and are more likely to die in hospital settings than their non-immigrant counterparts.<sup>5</sup> COVID-19, however, brings its own challenges in providing quality end-of-life care to immigrants. Specifically, immigrant patients are uninformed about ways to protect themselves or seek care early, and perhaps most tragically left to die alone.

The many things we rely on to ensure patients receive quality and value-consistent end-of-life care—legal documents such as living wills and health care proxies; the presence of a family member or loved one to advocate for one's care; and an ability to understand and navigate the healthcare system in the U.S.—are largely unavailable to immigrant patients. Add less access to quality care in general, as is the case for most hospitals in lower-resourced communities, and there emerge conditions predisposing to receipt of sorely suboptimal end-of-life care.

The foundation and central focus of most interventions designed to improve end-of-life care is getting patients to complete living wills and health care proxy forms. Yet, many immigrant patients are undocumented, putting them at a high risk of never completing these forms for fear that their undocumented status will be discovered. Higher levels of health literacy among immigrant patients also makes completion of these complicated forms a huge challenge. Combined, these risk factors put immigrants at a higher risk of receiving care not aligned with their own preferences.

Perhaps most critical to ensuring patients receive quality care is having informed loved ones present to advocate for patients' care in moments of emergency such as hospital admissions. Many immigrant patients are living and working in the U.S. while many or most of their family members live abroad. As such, these patients often lack local advocates for their care in the U.S., putting them at a high risk for receiving poor care at the end of life during hospital admissions. This reality has only been exacerbated by COVID-19, with restrictions around visitors as an additional barrier.

Immigrant patients also often confront linguistic barriers as non-native English speakers, an added challenge to navigating the complex U.S. healthcare system. If a patient is admitted to the hospital and in need of emergency care, they may experience a frustrating challenge in communicating their wishes and needs if English is not the preferred or spoken language. Often decisions must be made quickly, and translation services may or may not be available in moments of emergency. If health literacy is low, patients may not know about what treatments to ask for or may lack access due to poorly resourced hospitals which traditionally sit in communities serving immigrants.

Combined, these many system-level barriers put immigrants at high risk of receiving low quality care at the end of life. Recent health policy solutions have focused on addressing the vast racial and ethnic disparities in the COVID-19 pandemic. Unfortunately, many of these proposed solutions such as expanding access to Medicare and increasing the social safety-net risk leaving behind immigrants, especially undocumented ones. Community initiatives need to improve communication in underserved immigrant communities about how to advocate for the care they want at the end of life to ensure that patients receive quality care. Resourcing for hospitals in traditionally lower income communities must become a priority to equalize the care between hospital systems. And better attempts at connecting loved ones, even if abroad, need to be made earlier in the patient's illness to allow for advocacy and goodbyes, should they come, before the patient is no longer able to communicate.

We must design solutions that acknowledge and ameliorate the unique challenges and barriers that immigrants face when entering our healthcare system towards the end-of-life. As we turn towards a more

hopeful future, we cannot leave the most vulnerable behind in making system and policy level changes.

Megan J. Shen, PhD  
Weill Cornell Medical College, Department of Medicine, New York, NY, USA

Paul K. Maciejewski, PhD  
Weill Cornell Medical College, Department of Radiology, New York, NY, USA

Ana I. Tergas, MD  
Columbia University College of Physicians and Surgeons; New York Presbyterian Hospital-Columbia University Irving Medical Center, New York, NY, USA

Holly G. Prigerson, PhD  
Weill Cornell Medical College, Department of Medicine, New York, NY, USA

*Address correspondence to:* Megan J. Shen, PhD, 420 East 70th St., Suite 3 (LH 323), New York, NY 10021 USA.  
E-mail: [Mes2050@med.cornell.edu](mailto:Mes2050@med.cornell.edu)

<https://doi.org/10.1016/j.jpainsymman.2021.04.002>

### ***Disclosures and Acknowledgments***

Writing for this was supported by NCI K07-CA207580 (PI: Shen). The authors have nothing to disclose.

### ***References***

1. Chowkwanyun M, Reed Jr AL. Racial health disparities and Covid-19—caution and context. *N Eng J Med* 2020;383:201–203.
2. Institute of Medicine. *Dying in America: Improving quality and honoring individual preferences near the end of life.* Washington Ds: The National Academies Press; 2014.
3. Shen MJ, Prigerson HG, Tergas AI, Maciejewski PK. Impact of immigrant status on aggressive medical care counter to patient's values near death among advanced cancer patients. *J Palliat Med* 2019;22:34–40.
4. Tucker-Seeley RD, Abel GA, Uno H, Prigerson H. Financial hardship and the intensity of medical care received near death. *Psycho Oncol* 2015;24:572–578.
5. Tergas AI, Prigerson HG, Shen MJ, et al. Impact of immigrant status on location and quality of death among advanced cancer patients in the US. *ASCO Abstracts*. Submitted.