

Undocumented Immigrants with End-stage Renal Disease: The Case for Dialysis

Lilia Cervantes, MD; Philip Fung, MD; and Stacy Fischer, MD

Dr. Cervantes is an assistant professor and Dr. Fischer is an associate professor of medicine at the University of Colorado School of Medicine. Dr. Fung is an assistant professor of medicine at Saint Louis University School of Medicine.

Carmen was a 32-year-old Mexican woman with two elementary school-aged boys who first presented to our emergency department after six months of worsening nausea and vomiting, confusion, fatigue, and eventually shortness of breath. We discussed next steps with Carmen shortly after her stay in the intensive care unit, where she had been emergently dialyzed for a new diagnosis of end-stage renal disease (ESRD). The content of our conversation was unfortunately not unique and one we have too often at our safety net hospital. Carmen was undocumented. As she sat in her hospital bed with a tunneled catheter and the whirr of the dialysis machine in the background, we spoke about kidney failure and dialysis. We described the purpose of the kidney and how the machine would take the place of her kidneys by cleaning out her blood. We then spoke about how her undocumented status precluded her from receiving the standard of care. We went on to say that in Colorado undocumented patients with ESRD do not qualify for routine dialysis and that she would need to come in weekly when she felt ill enough to meet clinical criteria for admission to our hospital for emergent inpatient dialysis.

There are an estimated 11.2 million undocumented individuals in the United States with the majority being Latino and the largest subset being Mexican (52%).¹ Latinos have a nearly twofold higher incidence of ESRD compared to non-Latino whites, and there are an estimated 6,480 undocumented in-

dividuals with ESRD in the United States.^{2,3} US citizens have access to care under the 1972 law that established the Medicare ESRD program. If ineligible for Medicare, patients can receive coverage through Medicaid. Medical care for the undocumented with ESRD is fragmented and inconsistent across states.⁴ Under the 1986 Emergency Medical Treatment and Labor Act (EMTALA), undocumented individuals could not receive medical assistance unless they had an emergency medical condition. EMTALA is interpreted differently by each state and sometimes by individual hospitals within a state. For example, one state may consider the diagnosis of ESRD an emergency and provide dialysis care three times a week; in a neighboring state, a patient with ESRD may need to be critically ill (e.g. potassium greater than 6.0) before his/her care is considered an emergency. In addition to dialysis, there is a spectrum of what is offered with respect to primary ESRD care (e.g. treatment of anemia and hypertension) and dialysis access (e.g. arterio-venous fistulas vs. a tunneled catheter, which increases the risk of infection).

It was several months before Carmen understood that the care she received differed from those who were routinely dialyzed in the outpatient setting. Week after week, she presented to our emergency department with her two boys. Over the next six months, she became withdrawn and cried during her dialysis sessions. We came to understand that Carmen's only support had been her father, who was

deported weeks after she was diagnosed with ESRD, leaving her homeless. In addition to depression, Carmen had a substantial symptom burden and expressed a desire to withdraw from dialysis.

Patients with ESRD suffer a substantial symptom burden that is similar to that experienced by patients with advanced cancer and end-organ failure (e.g. heart failure, liver failure), including fatigue, decreased well-being, loss of appetite, and pain. There is very little research on Latinos with ESRD, and to our knowledge, there is no research on palliative care in undocumented individuals with ESRD. The available palliative care research on Latinos with other advanced illnesses suggests that compared to non-Latino whites, Latinos are less likely to die at home according to their wishes,^{5,6} less likely to have adequate pain management,^{7,9} and less likely to report a conversation about advanced directives.¹⁰

We gathered a multidisciplinary team and over the next two years effectively treated Carmen's depression and pain, helped her find stable housing, and began conversations about her values and goals. She was firm about her decision to withdraw from dialysis. She reasoned that she never wanted to be on dialysis but felt that there was no other option because stopping dialysis meant death and she did not want her children to be lost in the US foster system. She described having just one to two days each week during which she had enough energy to spend quality

continued on page 2

COMMENTARY

continued from page 1

time with her boys. She had survived three cardiac arrests and lived each day with the fear of another cardiac arrest that would break additional ribs and leave her eldest son even more emotionally traumatized because he was the person who always called an ambulance. The home we found for Carmen and her boys had legal services, and with their assistance, we worked with several adoption agencies until Carmen selected the parents that would eventually adopt her boys. Her last wishes were to spend time in the Rocky Mountains with her boys and foster parents and then travel to Mexico to die with her father caring for her. She passed away two years ago.

Many believe that the inconsistent care we offer this marginalized and vulnerable group is unethical.³ These patients are treated differently and below the standard of care because of their immigration status. While it is beyond the scope of this article to delve into all of the ethical arguments concerning the provision of health care for undocumented immigrants, a compelling argument can be made that while these individuals are not citizens, they remain a part of society, albeit often at the margins. Not addressing their needs is a way of ignoring their part in society and keeping them marginalized.¹¹

Other more practical arguments support routine hemodialysis for undocumented individuals with ESRD. Emergent care is 3.7 times more expensive than routine care.¹² The undocumented immigrant community is stable and does not migrate to the United States

specifically to access medical care.¹³ From a financial perspective, undocumented immigrants contribute significantly more money from unclaimed W2 taxes than the amount estimated to provide them with routine ESRD care.¹⁴ In contrast to the Centers for Medicare and Medicaid Services (CMS), which has implemented patient-centered quality measures into their value-based purchasing program (i.e. ESRD Quality Incentive Program),¹⁵ care has not changed for undocumented immigrants with ESRD, and there is little national leadership amongst nephrologists to improve their care. Our clinical experiences caring for Carmen and other similar patients have informed our ongoing research with this population. We are now conducting research that will provide a more in-depth description of the illness experience of undocumented Latinos with ESRD. This research includes a comparison of outcomes and utilization between undocumented emergently dialyzed ESRD patients and undocumented ESRD patients who receive routine dialysis. An observational cohort survey of documented and undocumented Latinos will help us understand their palliative care perspectives. Ultimately, we aim to develop a patient navigator intervention that will be culturally tailored to Latinos undergoing both routine and emergent hemodialysis to improve their palliative care outcomes.

References

1. Passel JS, Cohn D. Unauthorized immigrant totals rise in seven states, fall in 14. Available at: <http://www.pewhispanic.org/2014/11/18/unauthorized-immigrant-totals-rise-in-7-states-fall-in-14/> (accessed on July 24, 2015)

2. United States Renal Data System. Chapter 1: incidence, prevalence, patient characteristics, and treatment modalities. Available at: http://www.usrds.org/2014/view/v2_01.aspx (accessed on January 21, 2014)
3. Rodriguez RA. Dialysis for undocumented immigrants in the United States. *Adv Chron Kidney Dis* 2015; 22(1):60-5.
4. Hurley L, Kempe A, Crane LA, et al. Care of undocumented individuals with ESRD: a national survey of US nephrologists. *Am J Kidney Dis* 2009; 53(6):940-9.
5. Smith AK, McCarthy EP, Paulk E, et al. Racial and ethnic differences in advance care planning among patients with cancer: impact of terminal acknowledgement, religiousness, and treatment preferences. *J Clin Oncol* 2009; 26(25):4131-7.
6. Barnato AE, Anthony DL, Skinner J, Gallagher PM, Fisher ES. Racial and ethnic differences in preferences for end-of-life treatment. *J Gen Intern Med* 2009; 24(6):695-701.
7. Chiauzzi E, Black RA, Frayjo K, et al. Health care provider perceptions of pain treatment in Hispanic patients. *Pain Pract* 2011; 11(3):267-77.
8. Green CR, Anderson KO, Baker TA, et al. The unequal burden of pain: confronting racial and ethnic disparities in pain. *Pain Med* 2003; 4(3):277-94.
9. Anderson KO, Mendoza TR,

continued on page 3

COMMENTARY

continued from page 2

- Valero V, et al. Minority cancer patients and their providers: pain management attitudes and practice. *Cancer* 2000; 88(8):1929-38.
10. Kurella TM, Goldstein MK, Perez-Stable EJ. Preferences for dialysis withdrawal and engagement in advance care planning within a diverse sample of dialysis patients. *Nephrol Dialysis Transplant* 2010; 25(1):237-42.
11. Dwyer J. Illegal immigrants, health care, and social responsibility. *Hastings Cent Rep* 2004; 34(1):34-41.
12. Sheikh-Hamad D, Paiuk E, Wright AJ, Kleinmann C, Khosla U, Shandera WX. Care for immigrants with end-stage renal disease in Houston: a comparison of two practices. *Tex Med* 2007; 103(4):54-8, 53.
13. Zarembo A, Gorman A. Dialysis dilemma: who gets free care? *Los Angeles Times*, October 29, 2008.
14. Porter E. Illegal immigrants are bolstering social security with billions. *New York Times*, April 5, 2005.
15. Moss AH, Davison SN. How the ESRD Quality Incentive Program could potentially improve quality of life for patients on dialysis. *Clin J Am Soc Nephrol* 2015; 10(5):888-93.

SGIM