

Palliative Care Rounds

End-of-Life Care for Undocumented Immigrants With Advanced Cancer: Documenting the Undocumented

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Abstract

There are approximately 11.1 million undocumented immigrants in the United States, with a majority being Latino. Cancer is now the leading cause of death in Latinos. There is little research guiding providers on how to deliver optimal end-of-life care in this population. We describe a case of an undocumented Latino patient with advanced cancer, and provide a review of the literature on end-of-life care in undocumented immigrants. Our patient encountered many challenges as he navigated through the healthcare system in the last months of life. These included delayed diagnosis, limited social support, financial issues, fear of deportation, and language and cultural barriers, which resulted in significant physical and psychological distress. Within the undocumented patient population, there is often a lack of advance care planning, prognostic understanding, mistrust, religious practices, and cultural beliefs that may affect decision making. Given the growing number of undocumented immigrants in the United States, it is important for clinicians and policy makers to have a better understanding of the issues surrounding end-of-life care for undocumented immigrants, and work together to improve the quality of life and quality of end-of-life care for these disadvantaged individuals. J Pain Symptom Manage 2016;51:784–788. © 2016 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Emigrants, immigrants, health care disparities, Hispanic Americans, neoplasms, palliative care, terminal care

Introduction

There were approximately 11.1 million undocumented immigrants in the U.S. as of March 2011 according to the Pew Hispanic Center.¹ The majority of this population (76%) is Latino, with the majority residing in California, Texas, and Florida.¹ This population is expected to double in size by the year 2050.²

Cancer is now the leading cause of death in Latinos, accounting for approximately 33,200 deaths in the Latino population per year.³ Undocumented immigrants account for 14.6% of the uninsured population in the U.S. and represent the only population excluded from Medicare and the Affordable Care Act (also known as Obamacare).² Unfortunately, undocumented immigrants with cancer are at high

risk for inadequate care as they face not only the immigration system but a challenging health care system. Throughout the trajectory of illness, they are confronted with language and cultural barriers, limited social support, lack of access to care, underinsurance, and discrimination. There is a constant fear of deportation, which leads to a delay in diagnosis and ultimately a poor prognosis. The many medical, psychosocial, and logistical challenges related to the end-of-life (EOL) (i.e., last months of life) are often amplified in undocumented immigrants.

There is little research guiding providers on how to deliver optimal EOL care to this population. A better understanding of the unique challenges encountered by undocumented immigrants at the EOL represents the first step toward improving their quality of life

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and EOL care. Here, we describe a case of an undocumented patient with advanced cancer as he navigated through the health care system and provide a review of the literature on EOL care in undocumented immigrants.

Case Description

The patient was a young adult Latino man and construction worker who was admitted to our hospital after one month of progressively worsening back pain. An outpatient physician from a nearby clinic had previously referred him to physical therapy. Over time, ambulation became nearly impossible, and he was forced to quit his job.

The patient had lived undocumented and uninsured in the U.S. for several decades. He had no previous encounter with the legal or health care system and had no known comorbidities. He lived together with his wife and young children and was the sole breadwinner for his family. The already existing financial stressors significantly increased once the patient could no longer work.

The patient was fearful of going to see a doctor, and as the bills piled up, he did not want to spend money on an expensive medical visit. He did not want to risk the well-being of his family by potentially exposing his undocumented status. After a few weeks, his pain progressed and he subsequently visited a small community clinic. Plain films showed a large sacral lesion. He was referred to the emergency department at our institution.

On admission, spine imaging revealed vertebral lytic lesions and direct invasion of his distal spinal canal. A biopsy confirmed the diagnosis of cancer. During his hospital stay, he received his first chemotherapy treatment and radiation to the sacral mass. His hospital course was complicated by a large pleural effusion requiring intrapleural catheter insertion. He also had an extensive inferior vena cava thrombus and was anticoagulated. This was later stopped when he developed hematochezia related to colitis. The patient also underwent percutaneous pinning of his hip for a pathologic fracture.

As his hospital course continued, he became extremely anxious about how he would pay his bills without any medical insurance. His wife was not able to accompany him every day as she could not afford to go back and forth between her home, the hospital, and their children's school. She soon decided to take the children out of school and visited the hospital as often as she could as her husband approached the end of his life. She, too, became very preoccupied with the mounting medical expenses and voiced concern about this to the medical team.

Communication was difficult because the patient did not speak or understand any English. As the days passed, interpreters were not always present, particularly during brief encounters with the nurses and his medical team.

The patient and his wife considered returning to Mexico, expressing wishes that the patient be buried in his homeland. However, as they learned more about his terminal condition, they realized that this would not be possible given the risk of dying in transit and the cost they would incur even if it was possible.

The palliative care team became involved and was instrumental in providing adequate pain control and emotional support. After several emotional family meetings, the patient made the decision to change his code status and transition to hospice care on discharge. The social workers struggled to secure home hospice services given his uninsured and unfunded status. A local county indigent program was contacted, but he was denied because his car and property exceeded the resource limits. The patient and his wife were advised to appeal the denial letter. His wife was surprised and disappointed on receiving the denial. They were reminded that they were responsible for medical expenses incurred

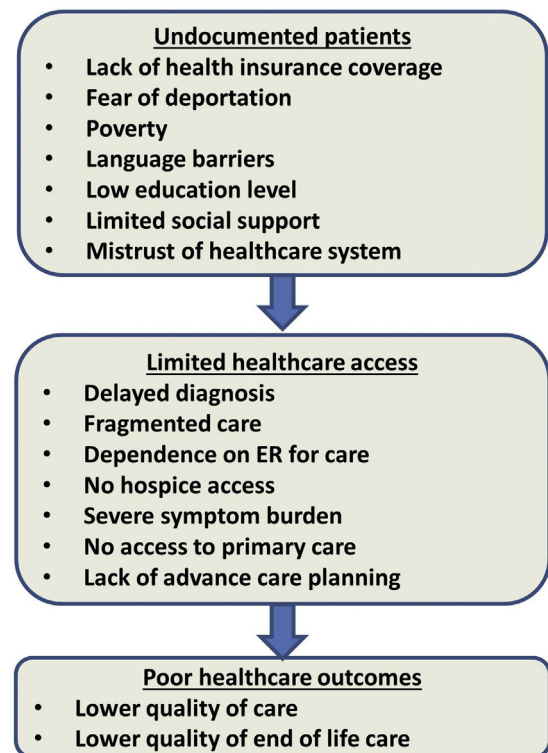


Fig. 1. Conceptual model of poor health care outcomes in undocumented patients. Undocumented immigrants have many risk factors that contribute to decreased health care access, ultimately resulting in lower quality of care and lower quality of end-of-life care.

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