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.

Keywords
Emigrants; immigrants; health care disparities; Hispanic Americans; neoplasms; palliative care; terminal care

Introduction
There were approximately 11.1 million undocumented immigrants in the United States 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).

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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 (ACA) (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) 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 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 were taken and a large sacral lesion was identified. 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 anti-coagulated. 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 upon 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 upon receiving the denial. They were reminded that they were responsible for medical expenses incurred during his hospitalization and were advised to contact the business center to make payment arrangements.

The social workers persisted in finding a funding source and after approaching many local hospice agencies, the patient was finally accepted as a charity patient. The patient was relieved to be able to leave after more than a month in the hospital. Upon discharge, he was prescribed morphine tablets but was not able to afford the prescription cost. Graciously, his relative stepped in and helped him pay for the medication. The patient died one month later at home surrounded by his family. Our multiple attempts to contact the wife afterwards were unsuccessful.

**Comment**

Of all the forms of inequality, injustice in health care is the most shocking and inhumane.

--Martin Luther King, Jr.

In this case presentation, we described the clinical course of an undocumented Latino patient with advanced cancer and highlighted multiple challenges faced by this patient as he navigated through the health care system at the EOL. These include 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 and healthcare outcomes (Fig. 1) (4–6). Given the growing number of undocumented immigrants in the U.S., it is important for clinicians and policy makers to have a better understanding of the issues surrounding EOL care for undocumented immigrants, and work together to improve the quality of life and quality of EOL care for these disadvantaged individuals.

Although there is a growing body of literature on undocumented immigrants in general, few publications have focused on EOL care. There has been some research conducted in undocumented patients with end-stage renal disease (ESRD) because this service is reimbursed for the undocumented patients in some states (7–9). Despite the prevalence of cancer, we found only three publications addressing EOL care in the undocumented oncology population—all were short commentaries each describing a patient (4, 5, 10). This case report thus contributes to the significant knowledge gap. Clearly, more research is needed as the EOL period presents unique challenges for undocumented patients.

As seen in this patient’s case, documentation status can affect almost every aspect of care. The fear of deportation is an ongoing threat in the daily life of an undocumented patient and this frequently leads to less participation in health care safety nets (11). Undocumented immigrants are often exploited in their workplace, compensated poorly, and may have the added stress of having to search for work on a daily basis (11). The traumatic separation from family and the persistent fear of deportation or detention can lead to severe mood disorders including post-traumatic stress disorder. According to the American Psychological Association (APA), the negative experiences endured by the undocumented immigrant population can interfere with a person’s sense of belonging, which is crucial for identity formation, and the inability to maintain long-term relationships, and result in distrust of authority and institutions (12).

A majority of foreign-born Latinos speak Spanish and less than one-fourth report fluency in English (13). This language barrier may negatively impact the patient-clinician relationship and the quality of care. In medical facilities with limited resources, it may be difficult to provide consistent interpreters. Bilingual family members may be asked to help but important information may sometimes be lost in translation. Inadequate interpretation services can result in serious medical errors, greater risk of infections, and longer hospital admissions (14). Furthermore, patients with limited English proficiency may struggle to learn about potential resources and support services and to make well-informed decisions about their care.

A low level of education, coupled with poverty, is another a major contributing factor adding to the challenges faced by undocumented patients at the EOL. Studies have shown that 47% of undocumented immigrants between the ages of 25–64 years of age have less than a high school level of education compared to 8% of the U.S. born population (15). The lack of education can result in language barriers and the patients’ ability to understand medical information. Furthermore, education level is associated with socioeconomic status, which partly explains why 20% of undocumented immigrants live below the poverty line compared to 13% of documented immigrant adults and 10% of U.S.-born adults (16). Financial
distress may be exacerbated at the EOL when the patient is no longer able to work and his care needs increase dramatically.

In the last weeks to months of life, social support is particularly important because of the patient’s deteriorating function. Unfortunately, the social network may be compromised for many undocumented immigrants because a majority of their close family members may reside in their home countries. The lack of insurance and financial concerns may further limit the support system. Many undocumented patients also lack family members who can financially support them, as many of their own relatives are undocumented and impoverished themselves. For example, the patient’s wife was his only visitor during the hospital stay. Interestingly, a recent report showed that undocumented immigrants were less likely than U.S.-born individuals to be in a single person household (13% vs. 30%), suggesting that they are not always without support (11).

Currently, it is estimated that 30% of undocumented immigrants have insurance through their employers or non-profit organizations (15); however, the ACA, first introduced in 2010, specifically excludes undocumented patients, which may make it even more difficult for them to seek insurance through their employers (17). For emergency care, uninsured patients can access the emergency rooms because the Emergency Medical Treatment and Labor Act (EMTALA) passed in 1986 mandated that providers medically stabilize patients when they present with a medical emergency, regardless of their ability to pay for services (18). Hospitals receive emergency Medicaid compensation for uninsured patients under these circumstances. Nevertheless, undocumented patients have lower rates of emergency room visits compared to citizens and other immigrants (19). For non-emergent care such as cancer treatments, access to the health care resources for uninsured undocumented patients varies widely, depending on the local access policies set by the hospitals and/or counties. Barriers to health care access ultimately translate to lower quality of care.

Undocumented patients often receive more aggressive care at EOL. Poverty, language barriers, fear of deportation, mistrust in the medical system, and exclusion of undocumented patients from health exchanges may all contribute to delayed diagnosis (19). In a National Cancer Database study, patients with lung cancer who were uninsured were much more likely to present with stages III and IV cancer at diagnosis compared to patients with private insurance (20). In turn, patients who present with more advanced disease often have greater symptom burden, fewer opportunities for EOL discussions, and receive more aggressive EOL care including prolonged hospitalizations, hospital death, and intensive care unit admissions, as seen in our patient (21–23). Moreover, hospice admissions among undocumented immigrants presents as a major challenge because access to hospice for uninsured patients is only possible through charity unless patients have the ability to pay. Thus, undocumented patients may be left with emergency departments and acute care hospitals as their only recourse.

A difficult decision at EOL is whether the patient should voluntarily return to his country of origin, or not. Ethically, some urge that since undocumented immigrants may not receive quality care in the U.S., we therefore should not deprive them of the standard of care they would otherwise receive back home. Others raise concern about the uncertainty of the
quality of care and resources they may have available in the country of origin. Logistically, it also may be difficult to transport an ill patient for long distances, which again raises ethical and legal concerns given the possibility of death in transit. Interestingly, some palliative care teams have reported that they were able to successfully transfer patients back to their native countries after assuring reliable travel arrangements and follow-up care (10). For example, Mexico’s protection department has paid for a patient’s plane ticket and designated a consulate staff member to escort the patient to Mexico. Upon arriving, a medical team awaited the patient and he was eligible to receive medical care through the government’s medical plan. It is not known at this time what proportion of undocumented patients die in the U.S. versus their homeland. The decision to travel home should be carefully considered and individualized. A related question is whether relatives can travel from the patient’s home country to visit the patient. Although temporary humanitarian visas are available, the stay is often authorized for a short term (i.e., weeks) and remains a challenge logistically.

Despite the growing number of undocumented immigrants, it is difficult to document the undocumented. Our case report contributes to the scarce literature available regarding undocumented cancer patients at EOL and highlights the unique challenges. Ultimately, how can we improve care for these individuals? Given the significant physical, emotional, social, and financial needs among the undocumented, early involvement of palliative care can help optimize the psychosocial care to patients and families through interdisciplinary care. Because a large majority of undocumented immigrants do not speak English, the use of a professional medical interpreter is imperative, particularly when addressing disease status, goals of care and advance care plans. Such discussions also should be tailored to the individual’s intellectual comprehension, emotional state and cultural background. Clinicians may benefit from a heightened awareness and more education on the care needs of undocumented patients, and be familiar with the scarce local resources available for undocumented patients. Because service availability and health care coverage for undocumented patients vary widely among states and even within each jurisdiction, it is important to contact the local authorities for more information. Researchers should conduct more studies in this vulnerable population. Ultimately, health care reform is needed to promote more equitable care for the most disadvantaged living among us.

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References


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.