Electric Repatriation for Undocumented Immigrants at End of Life

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Undocumented immigrants who become ill with a life-limiting illness are often faced with difficult choices and decisions to make. One decision with important advocacy implications for the palliative care nurse is whether the individual wants to spend the last few weeks and days of life in this country or his/her country of origin. Through a case study, some of the unique barriers undocumented immigrants face when they receive a diagnosis of a terminal illness and want to return home will be reviewed. Critical components of the nurses’ role in guiding the patient and family through an anticipated process of benefits and burdens as they contemplate returning to their country of birth will be described.

KEY WORDS
advanced practice nursing, ethics, palliative care, repatriations at end of life, undocumented immigrants

Repatriation of patients with terminal illness at end of life has become an area of increasing concern for palliative care nurses working in public hospitals or in hospitals with a significant immigrant, uninsured, or underinsured population. Through a case study, this article describes some of the unique barriers undocumented immigrants face when they receive a diagnosis of a terminal illness and want to return home. Critical components of the nurses’ role in guiding patients with terminal illness and their families will be highlighted. An advocacy and quality-of-life framework will be used.

BACKGROUND
Migration to the United States is not uncommon. As of 2012, there were 40.7 million immigrants living in the United States, and of these, 11.5 million were unauthorized (ie, not permanent residents or citizens). People migrate to the United States for a variety of reasons including those related to economics and to escape persecution. Some individuals will eventually decide to return to their country of origin, among these are the terminally ill who want to die “at home.” Given the increased number of migrants living in the United States, this number is likely to grow, and palliative care nurses will be faced with such situations with little guidance on how to proceed. “Forced” repatriation of the seriously ill unable to be cared for outside a hospital environment has been identified as another area of concern but is beyond the scope of this article. See Table 1 for definitions.

Case of M.J.
M.J.* is a 31-year-old woman from Guatemala who came into the United States from Mexico by illegally crossing the border. She received a diagnosis of lymphoma 3 years ago. Uninsured, she was treated at a public hospital and was receiving second-line chemotherapy. She was recently admitted to the hospital for bowel obstruction due to a large abdominal mass consistent with her lymphoma. Her bowel obstruction was treated conservatively with bowel rest and medications and resolved spontaneously after 2 weeks. Her hospitalization, however, was complicated by hospital-acquired pneumonia successfully treated with intravenously administered antibiotics. During this hospitalization, M.J. was being seen by a Spanish-speaking social worker who knew her well from the outpatient clinic. The palliative care team was also consulted early in her hospitalization because of concern by her oncologists that M.J. might not be a candidate for further chemotherapy despite her persistent and forceful requests that it continue. The oncologist asked that palliative care help clarify goals of care with the patient. M.J. informed the palliative care team that she wanted disease-directed care to continue. She understood her disease was not curable but wanted to live as long as possible. She also revealed to the palliative care nurse that she wanted to return to Guatemala to be reunited with her 2 children, 8 and 10 years old, and her spouse whom she has not seen in 6 years. M.J. stated she wanted to continue treatment before going back to Guatemala but also stated she wanted to return home if and when the chemotherapy was no longer working. M.J.

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*Aspects of this case have been changed to protect patient information.
was informed by the palliative care physician and advanced practice nurse that ongoing chemotherapy was unlikely to prolong her life in any meaningful way and would likely make her too weak to travel. She was asked to spend some time clarifying in her own mind how important it was for her to return home to see her family before she died. If this was a top priority she needed to make immediate plans to return home rather than delaying.

Obstacles revealed themselves when the logistics of returning to Guatemala started to be explored; examples were lack of money, no one available to travel with her, and not having a current Guatemalan passport to allow her to repatriate. Despite M.J.’s continued expression of desire to return home, she, as well as family and friends, seemed unable to complete the tasks needed to get her home. M.J. was debilitated from her prolonged hospitalization and advanced disease; specially tailored physical therapy was advised so that she could tolerate the plane ride but she was “unwilling” to participate. The reason was unclear. An evaluation by a psychiatrist ruled out a clinical depression, and she remained under the care of her social worker. M.J. continued to deteriorate, her bowel obstruction reoccurred, and the sicker she became, the more adamant she was about going home. With concerted effort by the palliative care team working with the patient and her family and friends and access to some philanthropic funds, plans were eventually completed to enable her to return home. The day prior to her flight, however, M.J. acknowledged that she was too weak to travel and called her children and spouse to tell them that she would not be able to return home. Her flight, for some reason, was not immediately cancelled. Just hours before the time her flight was scheduled to depart, M.J. left the hospital AMA accompanied by family and friends and went by car to the airport. She quickly decompensated at the airport and lost consciousness. Emergency medical services were called, and M.J. was found unresponsive. She was transported to a nearby hospital where she later died a few days later.

### DISCUSSION

Undocumented immigrants who become ill with a life-limiting illness are often faced with difficult choices. Initially determining how to get adequate medical care can be very difficult, if not impossible. If after accessing care at a public hospital the disease progresses, where the patient would want to spend his/her last weeks and days of life, either in this country or his/her country of origin, becomes an important choice. The earlier these discussions are held in the disease trajectory, the better, as there are many hurdles to overcome.

An undocumented immigrant’s choice to repatriate home at the end of life can be influenced by many factors including the lack of access to health care and caregivers outside the hospital, especially if not eligible for Medicare or Medicaid. Although emergency Medicaid does provide for emergency medical care for undocumented immigrants and some nonimmigrants, coverage varies from state to state but does not usually extend far beyond the care received in the hospital. This restriction limits access to home care services and long-term care facilities, although some charity care may be available through home hospice programs. In some instances, undocumented migrants may be eligible for employer-sponsored insurance and primary care through federally qualified health centers. Because of these limitations to home care, the patient may hope, and sometimes have unrealistic expectations, that needed care beyond the hospital not available in this country will be available to them if they return to their country of origin.

### Starting the Conversation With M.J.

The oncologist and psychologist had been clear with the patient that her disease was not curable and that further chemotherapy would likely not prolong her life or improve the quality of her life and might indeed shorten her life. The team understood that 2 things were important to M.J.: (1)
that she live as long as possible and was willing to accept any treatments that achieved that outcome and (2) that if chemotherapy was no longer working she wanted to return to her home country and be reunited with her husband and 2 young children. The palliative care team was asked to continue these conversations, make sure that M.J. thought through the possible benefits and hardships of returning to her home country, and help facilitate her return home if that was her ultimate decision. Truthfulness, clinical sensitivity, and accommodation were central to these discussions (Table 2).9

The palliative care nurse assumed the central coordinating role with the team and patient as well as with the oncologist and social worker.

Steps
First, in order to have a better understanding of the patient’s cultural background and the likely environment she would be returning to, the nurse, working with the social worker who spoke Spanish and had a good relationship with the patient, completed a cultural assessment. An example of cultural assessment questions is seen in Table 3.10

Assessment revealed that the patient was Mayan by background and a devout Catholic and lived in a rural area. She had come to this country to escape poverty, to work, and to send money back home to support her 2 children and disabled husband. She came from a large extended family. Her goals were clear—to live as long as she could, and she was willing to accept any treatment to achieve that end—but, if she was dying, she wanted to go back to her native home and be reunited with her husband and children. She had formed relationships in this

### TABLE 2 Ethical Concepts

- **Truthfulness** fosters trust and demonstrates respect when told in a compassionate and sensitive manner and titrated to the patient’s ability to absorb the information. Truthfulness is more than disclosure of information but is also the meaning of the information to the patient. Truthfulness is necessary so that the patient can make an informed choice.

- **Clinical sensitivity** implies attunement to the impact of the patient’s illness on his/her overall well-being and quality of life.

- **Accommodation** is a reciprocal process and can be complicated in the palliative care arena where many people are involved in the patient’s care and trying to actualize the patient’s goals, including the patient, family members, friends, and members of the health care team. That was the situation in M.J.’s case.

- **Advocacy** is a primary role of nursing. It entails helping the patient to reach a decision that expresses all that he/she believes is important about self and the world—the entire complexity of one’s values including contradictions and conflicts re-examined and clarified in this new context.

### TABLE 3 Key Cultural Assessment Questions

- **Tell me a little bit about yourself** (eg, your family, your mother, father, siblings, etc).

- **Where were you born and raised?** (If an immigrant, “How long have you lived in this country?”)

- **What language would you prefer to speak?**

- **Is it easier to write things down, or do you have difficulty with reading and writing?**

- **To whom do you go for support** (family, friends, community, or religious or community leaders)?

- **Is there anyone we should contact to come to be with you?**

- **I want to be sure I’m giving you all the information you need. What do you want to know about your condition?** To whom should I speak about your care?

- **Who do you want to know about your condition?**

- **How are decisions about health care made in your family? Should I speak directly with you, or is there someone else with whom I should be discussing decisions?**

- **(Address to patient or designated decision maker) Tell me about your understanding of what has been happening up to this point. What does the illness mean to you?**

- **We want to work with you to be sure you are getting the best care possible and that we are meeting all your needs. Is there anything we should know about any customs or practices that are important to include in your care?**

- **Many people have shared that it is very important to include spirituality or religion in their care. Is this something that is important for you? Our chaplain can help contact anyone that you would like to be involved with your care.**

- **We want to make sure we respect how you prefer to be addressed, including how we should act. Is there anything we should avoid? Is it appropriate for you to have male and female caregivers?**

- **Are there any foods you would like or that you should avoid?**

- **Do you have any concerns about how to pay for care, medications, or other services?**


country, but none were as important as those at home. She had not thought through the logistics of getting home or what medical care would be available there and assumed God and her family would take care of this for her.

Second, with this as a background, the nurse started to determine what resources were available to get M.J. home including (1) contacting the embassy to facilitate a new passport and possible assistance in her transport home,
(2) finding philanthropic funds to help pay for the her airfare and those of an accompanying friend, (3) communicating with an airline to understand the requirements of transportation of a critically ill person, (4) locating a physician willing to take responsibility for M.J.’s care once in Guatemala, (5) ascertaining her final destination once in Guatemala and who would arrange the transportation to get her there from the airport, and (6) the availability of necessary medications to manage her symptoms once home. These were time-consuming tasks.

The team was able to reach the husband by telephone to evaluate his ability and that of the extended family to care for his wife once home. As M.J. had indicated, the team confirmed there was space in the house and that she would be cared for. Once it was clear that she wanted to go home, a physician was located who agreed to assume her care in Guatemala, and the plan was to provide her with a 1-month supply of medication to tide her over the transition period to home. At this time, M.J.’s prognosis was less than 2 months.

The necessary paperwork for the airlines was in place, and a friend was willing to undertake the journey with her. Transportation from the airport in Guatemala to her home was still unclear. With some misgivings, the team agreed to discharge her, but the day before her flight, M.J. felt unable to make the trip and let her family know that she would not be coming home. What made her change her mind at the last minute, sign out against medical advice, and travel to the airport where she became unresponsive and later died is not known. The staff felt there was something they had missed in this patient’s care and felt unsettled and upset by the manner of her death.

**Reflection and Deliberation**

This case presents issues unique to undocumented immigrants from developing countries who have advanced progressive disease and decide to return home to their country of origin when close to death. Access to the kind of medical care they had received in the United States is frequently lacking. Extended families provide all the care and support that they can but with limited medical resources and backup. Patients like M.J. may delay returning home until their physician tells them that disease-focused treatment is no longer an option. In many disease processes, by the time this conversation takes place the patient’s functional status is poor, and they find themselves in a situation where they are too ill to undertake the journey home.

Nursing advocacy for these patients, as previously outlined, requires attentive listening, truthfulness, clinical sensitivity, and accommodation in order to really understand what the patient is striving for. What is motivating the patient to make this choice, what responsibilities do health care providers play in helping the patient achieve the goal of repatriation, and what role do nurses play in protecting patients when there is perceived harm in the patient traveling or dying in their home country with inadequate care? The case provides a framework to explore several important issues and lost opportunities where skilled palliative care and hospice nurses can make a huge difference to the patient’s sense of agency through skilled communication around values, options, and choices.

Getting the patient home and reuniting them with their family can provide such a strong and compelling narrative—it is something health care providers would want for themselves—that providers are sometimes blinded to the patient’s best interests and to exploring what the patient is really striving for and how it can be achieved. Similarly, the patient’s desires to return home at such a vulnerable time may prevent the patient from seeing what is really possible and in their best interest. In addition, as outlined earlier, it is essential for health care professionals to be aware of the health care system the patient is returning home to; whether the care they need, including opioids, to manage pain is available and if there is a physician who is willing to accept the care of the patient and with whom the palliative care team can communicate; if opioids have limited availability in the country the person is returning to, and how large a supply you can give to the patient to take with them; and what is involved in an airline accepting the patient, such as whether he/she needs 2 seats rather than 1 seat to accommodate his/her needs and whether he/she needs a medical letter to show to the security screeners if asked about his/her prescription of opioids for pain. A checklist for these very concrete travel related issues is helpful (Table 4).

Because money and safety were issues for M.J. on her flight home, exploring the possibility of an air ambulance was important; however, this can often be cost prohibitive. The relevant embassy may also be helpful in some situations, but this is very variable. If the patient was too sick to travel, was it possible to get a visa and financial help for M.J.’s husband and 2 children to come to the States to see her here? Exploring these issues when time is limited, as well making preparations for as safe a travel plan as possible, is extremely time consuming for a patient such as M.J.

Early involvement of palliative care with goals-of-care discussions with patients and families is a fundamental part of good-quality palliative care. Having goals-of-care discussions earlier in the disease trajectory has been shown to improve quality of life. In this case, it is likely that earlier involvement in palliative care with realistic goals-of-care discussions that took the entire natural history of disease progression into account may have led to earlier discussions with the patient about the right time to return home. The physicians may have been able to give clearer treatment recommendations taking the patient’s goals into account. Specifically, recommendations on when to stop
chemotherapy to ensure time and physical reserve for the patient to travel were needed. M.J. was not a candidate. Even if her functional status could be improved, the best therapy that could have been offered according to a recent systematic review would have looked like, but my guess is a young mother struggling with the desire to live longer, fulfilling her goals for moving to this country, and being with her children.”

Another question evident in this case is our obligation to do what is in the patient’s best interest. But who decides this—surely the patient with capacity—but that implies that the patient has been fully informed of the benefits and burdens of the various options and perhaps alternative ways of reaching her ultimate goal. There is evidence that patients with very poor functional status have been able to travel without incidence. There is also evidence to the contrary, with patients dying in route or suffering severe complications. There is not a good understanding of the impact that flying poses on people with serious illnesses. In the case of M.J., the nurses felt they were doing the right thing, because they were constantly assessing what the patient wanted and trying to help her achieve this journey home. A call to the ethics committee may have helped sort out some of these issues.

The team often wondered why the patient made that fateful decision at the last minute to leave for the airport. Was she in panic? She had already said goodbye to her children, telling them that she could not make it. Perhaps she did not want them to live with that narrative, that their mom died quietly in a bed far away. Instead, she may have wanted them to always know that she died trying, and she did not give up, even in the last minutes of her life. In debriefing about the case, 1 nurse said the following: “As I was getting ready to leave the room the last time I saw her, she grabbed my hand as I turned to walk away. I looked into her eyes, and very calmly and peacefully she said to me that ‘it is not your fault.’ That struck me. I don’t look at this case through the lens of fault but that implies that it is not your fault.”

There are several measures that may improve elective repatriation for patients at the end of life. Suggested actions include the following:

1. Address how repatriation fits into the patient’s goals for end-of-life care. This needs to be done early in the disease process.

### TABLE 4 Travel Checklist

- Airline ticket or finances to be able to afford a ticket
- Documentation that will allow reentry into their country (usually a current passport from the patient’s country of origin). Emergency documentation for reentry can be obtained from some consulates.
- Necessary medical and nursing care established in the country where patient is returning to. (Family members living in the country can sometimes help set this up. In more remote areas, the foreign government may be able to organize this, or help may be able to be obtained through the International Red Cross.)
- Transportation to the airport in the United States
- Plan in place on how to deal with anticipated symptoms when on the plane
- Prescription medications in their original bottles
- Appropriate assistance secured at the airport and on the airplane (wheelchair at the airport, travel companion, letter from physician, plan for bowel and bladder elimination)
- Appropriate accommodations at layover airports. (Contacting these airports or the International Red Cross may be helpful)
- Transportation from the destination airport to home or hospital.
2. Be transparent when repatriation is addressed. Make sure that the patient understands it is not a recommendation but just a recognition that for some people repatriation may be important.

3. When repatriation is clearly identified as a goal of the patient before the end of life, provide recommendations for medical care with this in mind.

4. If staying in the United States to continue treatment will likely result in the patient becoming too debilitated to travel, make sure the patient/family understands this so that they can make informed decisions. Educate patients about the “window of opportunity.”

5. Try to understand the reasons for the patient wanting to go home. Does the patient want to go home to reunite with family? Does the patient want to die in his/her home country, so he/she can be buried there to avoid the high cost of transporting a body after death? Does the patient want to return to his/her birth country because there is family there available to provide needed care? Such information will not only help to understand someone’s goals, but also help direct care to meet these goals if travel is not possible.18

6. Does the patient/family understand the risks of flying? Recommend they contact the airline to inform them of the patient’s medical needs. Provide a medical letter as needed.

7. Let the patient know when your assessment is that it is too risky to fly and that you do not recommend it.

8. Recognize that clinicians may identify so strongly with the patient’s desire to go home (counter transference) that it clouds judgment. It is hard to recommend to a patient not to travel back to see family, especially if there is a strong sense that that is what we as clinicians would want for ourselves. Our own narrative may prevent us from being entirely honest with the patient/family and become a barrier to really “hearing” them.

9. Ensure adequate support on the flight home.

10. Work with the patient, family, and medical services in the home country to ensure that the patient will get the needed medical care when returning to the home country. The patient’s native country’s consulate may also be able to help identify appropriate medical and nursing resources to ensure adequate care.

**SUMMARY**

Addressing a patient’s desire for repatriation at the end of life should be incorporated early into goals-of-care discussions. This includes a clear understanding of the reasons for the patient’s choice. Utilizing ethical principles such as transparency, clinical sensitivity, advocacy, and accommodation when working with immigrants who choose to return to their country of birth can help achieve a more objective approach in efforts to do what is best for the patient.

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**References**


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