

Kelly Ferraro, MD

Division Chief, Palliative Medicine,
Denver Health and Hospital Authority,
Denver, CO; University of Colorado
School of Medicine, Aurora, CO

Sandhya Sharma, MD

Denver Health and Hospital Authority,
Denver, CO; University of Colorado
School of Medicine, Aurora, CO

Kimberly A. Indovina, MD

Denver Health and Hospital Authority,
Denver, CO; University of Colorado
School of Medicine, Aurora, CO

Providing comfort: Caring for patients who wish to die in their home country

IN AN INCREASINGLY GLOBAL WORLD, medical teams must be adept at caring for patients who have immigrated. This includes responding to requests to ensure comfort for patients who, after maximizing disease-directed treatments, wish to return to their country of origin to die.^{1,2} This article offers a framework for responding to these requests with equitable patient care.

See related editorial, page 275

■ TIMING CONSIDERATIONS

Disease trajectories vary. For example, patients with advancing cardiac or pulmonary disease may experience increasing exacerbations punctuated by partial recoveries. Patients with cancer often maintain high physical function until weeks before death, when their functional status declines sharply. It is important to start discussions early enough that, if a patient wishes to return to their country of origin, they are physically able to travel. Families, recognizing that the patient wants to be buried in their country of origin, may have practical concerns about the possibility of travel, and these should be addressed. We evaluate each patient's functional status and likelihood of death during planned travel.

There are realistic options for travel in the setting of terminal illness. Travel can be considered between treatment cycles, when symptoms are relatively controlled, or after all disease-directed treatments have been maximized. A patient may be frail but also clinically stable. For a journey of many hours or even a few days, we generally recommend that the patient be cognitively interactive, able to take medications by mouth, and mobile with single-person support. At this minimum level of function, there is a life expectancy

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of many days to several weeks and a high likelihood that the patient will successfully travel home. When a patient's functional status declines beyond this point, we initiate a conversation to recommend that goals be shifted away from travel.

■ TRAVEL OPTIONS

The planning process must include discussion of mode of travel, the anticipated time frame, assistance that will be required, and types of help available along the way.^{3,4} Patients most commonly intend to drive or to fly via a commercial airline to return to their country of origin. Preparing the family to manage eventualities can avoid unnecessary distress during travel.

Questions to ask and resolve during planning include the following:

- Can the patient tolerate the trip physiologically? For example, can their oxygenation be safely maintained in a plane?
- What are the logistics of the journey? Will they stay somewhere overnight, or is the family taking shifts to drive straight through?
- What are the patient's physical requirements? Can they remain upright in an airline or automobile seat for the duration of the trip? Will they need a wheelchair or other assistive device to help with transfers?
- Is there a system in place to manage possible incontinence, the need to physically help the patient toilet, and the control of other symptoms?

■ MEDICATION MANAGEMENT AND ADMINISTRATION

Patients may require medication for comfort or disease modification or both, and their families will need information and training for medication management while traveling.

TABLE 1
Examples of medications to consider for travel comfort care

Indication	Medications	Considerations
Long-acting pain control	Fentanyl patch Methadone Morphine extended-release	Current and predicted pain Prior pain medication use, familiarity, and tolerance Future ability to take oral medications
Breakthrough pain or dyspnea	Morphine sulfate oral solution	Can be used when patient loses ability to purposefully swallow
Terminal fever or pain	Acetaminophen	Pills can be used orally or rectally Low risk of diversion
Nausea and vomiting	Ondansetron Promethazine	Consider if single medications can be used for multiple symptoms
Pain, nausea, cancer-related swelling, or obstruction	Dexamethasone	Multimodal effect Benefits usually maximized over 2 weeks Use cautiously if hyperglycemia is a concern
Terminal agitation, anxiety, seizures, and nausea	Lorazepam Olanzapine Haloperidol	Useful for spectrum of symptoms in terminal phase
Constipation	Bisacodyl Polyethylene glycol	Bisacodyl oral pill can be used rectally when patient loses ability to swallow
Secretions, death rattle	Atropine 1% drops	Coach family on repositioning

Therapy for comfort

Standard hospice practice in the United States includes creation of medication packs for patients that achieve comfort quickly in a home setting.⁵ Home hospice medication packs may vary because of availability, pharmacy formulary, cost, insurance coverage, and specific patient needs.⁶ The preparation of comfort care packs for terminally ill patients with cancer returning to their country of origin is similar to that used in US hospice practice, but has unique challenges. As a component of equitable and culturally sensitive care, we provide medications and coaching for patients and their families to use during and after travel to their home country.

Table 1 offers examples of medications to consider including in a comfort pack. We create regimens that are simple to administer, favoring pills or liquids that are administered orally or rectally and prioritizing medications that can be used for multiple symptoms, such as opioids for pain or dyspnea, to ensure success. Interdisciplinary teamwork is critical to ensure both the availability and practicality of medications for each patient after discharge. Depending on the patient’s prognosis, we recommend prescribing a 1-week to 1-month supply of medication to balance patient care and safety.

Therapy for disease modification

A review of all medications with consideration of whether they still provide comfort can help alleviate polypharmacy as the patient’s goals change. For example, some patients may desire to continue oral anticancer therapy as long as possible. Because oral anticancer medications may be unavailable in patients’ home countries, our oncology team sometimes prescribes up to a 1-month supply if these medications are thought to be of benefit. Medications such as diuretics and antiarrhythmics provide patients comfort while they are alert and should be continued, but statins may have decreased benefit in the last months of life. Shared decision-making between the patient and their medical team can help to determine which medications to continue.

Medication safety

Comfort medication packs provided to home hospice patients are designed to be used with clinical oversight. Terminally ill patients returning to their country of origin will not have this ongoing oversight from the prescribing team, who must feel confident that they are doing no harm. To ensure excellence in patient care, it is critical to train families in the use of medications,

provide clear instructions, and evaluate who may be able to guide the family after their arrival—for instance, local medical staff or medically trained family members.

Before travel, we recommend that families receive bedside training from experienced nursing staff in medication administration and physical care of the patient. The intent is to create a safe environment for the patient when they are no longer actively under the care of the medical team. This preparation allows family members to assess their ability to care for the patient and gain confidence with tasks such as medication preparation, rectal administration of pills, dressing changes, and physical transfers.

We advise patients and caregivers or travel companions to carry medications in their labeled prescription bottles and with the original prescriptions intact. We recommend keeping them in carry-on bags to prevent loss or theft. As laws vary by country, we counsel patients and families to be aware of laws that may regulate entry with certain medications.

DOCUMENTATION OF END-OF-LIFE DECISIONS

Patients, families, and clinicians all share concerns about death in transit. We recommend travel only when we believe that the patient will successfully complete the journey, but we also recognize the frailty of these patients. We recommend that patients and their travel companions carry these documents:

- A letter that summarizes the patient's medical conditions, clinical status, and medications
- Copies of advance directives, including medical power of attorney and orders for life-sustaining treatment (eg, Medical Orders for Scope of Treatment or Physician Orders for Life-Sustaining Treatment forms).

We provide statements regarding the patient's current medical illnesses but do not make any guarantees

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of safety during flights. Airlines make their own determinations regarding safety of travel as patients board the plane.

In-flight death is rare, comprising 0.3% of nearly 11,000 in-flight emergencies reported to a physician-directed communications center from January 2008 through October 2010.⁷ International guidelines purposefully permit airlines and their crews a wide range of responses to in-flight passenger illness and death.⁸ Patients and families should be advised that no worldwide guidelines exist for airlines regarding completion of flight or diversion to the nearest airport should a passenger die on board.^{3,4} To minimize or avoid distress, we recommend a proactive discussion of this scenario that involves all parties—travel companions, the medical team, and the patient. The flight crew's response to an in-flight emergency may be influenced by several factors, including the patient's or accompanying family member's ability to relay their medical information and goals of care, the resources and training of those on board, and cultural comfort with the possibility that the patient may die on the plane.

A STARTING POINT

Providing counsel to terminally ill patients wishing to return to their country of origin is an academically challenging endeavor that many medical teams face. It is also one of the most professionally gratifying scenarios we encounter as we meet the patient's goal of returning home. We hope that this discussion can guide other medical teams with end-of-life care and serve as a starting point for further discussion and guidelines.

DISCLOSURES

The authors report no relevant financial relationships which, in the context of their contributions, could be perceived as a potential conflict of interest.

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Address: Kelly Ferraro, MD, Palliative Medicine, Denver Health and Hospital Authority, 777 Bannock St, MC 4000, Denver, CO 80204; Kelly.Ferraro@dhha.org