Far from Home and Facing Serious Illness: Palliative Care for Undocumented Immigrants

Presenter: Anne Kinderman, M.D.

May 3, 2016 - 12-1:30 pm
Providence St. Vincent Medical Center

May 4, 2016 - 12-1:30 pm
Providence Portland Medical Center

Donor contributions to Providence St. Vincent Medical Foundation make this lectureship possible.
Established in 2006, the Goldman-Berland Lectureship in Palliative Medicine honors two Providence St. Vincent Medical Center physicians, Robert Goldman, MD, and John Berland, MD. These physicians have been recognized for their outstanding whole-person patient care and for being advocates and innovators in palliative care. Dr. Goldman was a medical oncologist who helped initiate the Providence Home Hospice Program in the 1970s. Dr. Berland, a retired general internist, has a passionate interest in palliative care, and wants to make sure that Providence clinicians know how to provide excellent care for patients with advanced chronic, life-limiting or terminal illnesses.

The Lectureship is a funded program of the Providence Center for Health Care Ethics. The Center was established in 2000 and contributes to excellence in health care by providing ethics education, consultation, research and scholarship. The Center also supports palliative care by coordinating palliative care efforts throughout the Oregon region of Providence Health & Services, and by sponsoring educational opportunities in palliative care, such as a palliative care elective for Providence internal medicine and family medicine residents.

The Goldman-Berland Lecturer is a clinician recognized nationally for excellence in palliative and end of life care. Previous Goldman-Berland scholars and their Medical Grand Rounds topics include the following:

2007 - Steven Pantilat, MD, FACP, Founding director of the Palliative Care Service at University of California San Francisco Medical Center, and professor of clinical medicine in the Department of Medicine at UCSF School of Medicine. Palliative Care: What It Offers Patients and Clinicians.

2008 - Ira Byock, MD, Director of Palliative Medicine at Dartmouth-Hitchcock Medical Center, Chair of Palliative Medicine at Dartmouth Medical School in Lebanon, New Hampshire. What Are Doctors For? The Physician-Patient Relationship through the End of Life.

2009 - Judith Nelson, MD, J.D., Associate director of the ICU at Mt. Sinai Medical Center and professor of medicine, Mt. Sinai Medical School of Medicine, New York City. Palliative Care in the ICU: Closing the Gap Between What We Know and What We Do.

2010 – Kathleen Puntillo, RN, DNS, FAAN, Professor emeritus of nursing and research scientist at University of California, San Francisco with ongoing clinical practice in critical care nursing. The Epidemic of Procedural Pain in Acute and Critical Care.

2011 – Mary Hicks, MSN, APN-BC, Palliative Care nurse practitioner and Elizabeth DiStefano, RN, BSN, Palliative Care administrator, St. John Health System, Detroit, MI. How Palliative Care Transformed Our Hospital: Lessons from Detroit.

2013 – Angelo Volandes, MD, MPH, Faculty at Massachusetts General Hospital and Harvard Medical School, Boston, MA. Patient Decision-Making in 2013: How Video Tools Break Down Barriers in the ICU/Clinic.

2014 – Erik Fromme, MD, MCR, FAAPM, Medical director of Oregon Health & Science University Palliative Care Service, assistant director of OHSU Center for Ethics in Health Care and associate professor of medicine, nursing and radiation medicine, Portland. Jocelyn White, MD, FAAPM, FACP, FAAPP, Medical director of Legacy Hospice and Hopewell House, Portland. Communication Tools for All Inpatient Admissions.

2015 – Michael Rabow, MD, FAAPM, Professor of Clinical Medicine and Urology at the University of California, San Francisco, director or Symptom Management Service at the Helen Diller Family Comprehensive Cancer Center, director of Symptom Management & Palliative Care Consultation Service at UCSF/Mount Zion Hospital. The Evolution of Palliative Care: What All Providers Need to Know.
Dr. Anne Kinderman is an Associate Clinical Professor of Medicine at the University of California, San Francisco, and is the Director of the Supportive & Palliative Care Service at San Francisco General Hospital. After completing her Internal Medicine Residency at University of California San Francisco and Hospice & Palliative Medicine Fellowship at Stanford, she returned to San Francisco General in 2009, to help develop the Supportive & Palliative Care Consult Service, as its founding Director.

Dr. Kinderman’s scholarly work has included developing a curriculum in palliative care interpreting for professional medical interpreters, promoting high-quality care for vulnerable patients with serious illness, and expanding palliative care services in safety net health systems. Within the American Academy of Hospice and Palliative Medicine, she helped to create and lead a Special Interest Group focused on the healthcare Safety Net, which advances collaboration and scholarship among palliative care providers caring for vulnerable patients.

In 2014, she received a Sojourns Scholars Leadership Award from the Cambia Health Foundation, to support her development as a leader in Palliative Care, and was subsequently named an Inspiring Leader Under 40 by the American Academy of Hospice and Palliative Medicine.
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EVALUATION SURVEY for In-Person Attendance

Far from Home and Facing Serious Illness:
Palliative Care for Undocumented Immigrants
ATTENDANCE AT PROVIDENCE ST. VINCENT OR PROVIDENCE PORTLAND MEDICAL CENTER

The Providence Center for Health Care Ethics offers Continuing Education Credit of 1.8 nursing contact hours and 1.5 AMA PRA Category 1 credits™ for this presentation. If you wish to receive CEC, completion of the online evaluation survey as well as signing in at the registration table are required.

The deadline for completing this survey is Friday, May 13. Certificates will be delivered the week of May 23rd to the email address you include on this survey.

TO COMPLETE SURVEY:

We appreciate feedback from all who view this presentation whether or not you wish to receive accreditation. All responses to this survey are confidential.

Questions about this survey or CEC may be directed to Patty Goss at patricia.goss@providence.org or 503.216.1906.
Far From Home and Facing Serious Illness: Palliative Care for Immigrants
Open Forum, May 2016
Anne Kinderman, MD

Basics of Immigration
- Documented immigrants
  o Designations
    - On visas -- family, work, special circumstances (e.g. human trafficking)
    - Green card holders -- "Lawful Permanent Residents"
    - Naturalized citizens
  o Eligible for coverage under Medicaid, ACA, Commercial Insurance, (Medicare)
- Undocumented immigrants in US
  o 11.3 million undocumented migrants in US in 2014 (Pew Research Center)
    - 120,000 in Oregon as of 2012
    - Number of new undocumented immigrants each year roughly matches those who leave voluntarily or are deported (total number ~stable since 2009)
    - Most have been in US for 10 years or more (61%)
    - Majority from Mexico and Central America, young (25-44)
  o Health insurance eligibility
    - 43% of undocumented migrants estimated to have some insurance coverage
    - Undocumented migrants (UDMs) may be eligible for:
      - Employer-sponsored insurance
      - Emergency Medicaid
      - Long-term care Medicaid (some states)
      - Primary care through Federally Qualified Health Centers
    - UDMs and Legal Residents in US <5 yrs are NOT eligible for plans under health exchanges or private insurance, full-scope Medicaid, or Medicare

Common Issues/Concerns for Immigrants with Serious Illness
- Dual identities
- Importance of homeland traditions
- Ability to work associated with identity, survival
  o Often have a range of dependents
  o Physical illness may be immediate financial threat, often can’t access disability
- Isolation from family/friends
  o Limited caregiver(s)
  o Limited local surrogate(s), or key decision-maker lives abroad
- Fear of deportation, or exposing friends/family to risk of deportation
  o May give incorrect address
  o May be reluctant to accept home services
- Language barriers
- Cultural barriers
- Dying preferences
  o Place of dying
  o Final resting place
  o Religious rituals for time of mourning
  o Remembrance by family in subsequent years
Checklist to Facilitate International Travel for Patients at the End of Life
from Deamant C et al, Journal of Palliative Medicine 2014

1. Assess ability to tolerate commercial airline travel
   o Basic requirements
     • Awake and alert, stable vitals
     • Able to sit upright for at least 4 hours or duration of flight
     • Able to tolerate fluids and medications either orally or enterally
     • Escort available (if patient too weak to travel alone)
   o Assess for relative contraindications -- If travel contraindicated, see #5 below
     • Oxygen support > 4 L/min by nasal cannula
     • Required intravenous support
     • Airborne communicable diseases
     • Myocardial infarction within 7 days or Stroke within 3 days
     • Anemia with hemoglobin less than 7.0 g/dL
     • Surgeries (major) within 5–10 days
     • Increased intracranial pressure
     • Pneumothorax (suspected or confirmed)
     • Untreated acute deep vein thrombosis
     • Psychiatric disorder complicated by unstable, aggressive, or unpredictable behavior(s)

2. Travel preparations
   o Determine travel arrangements
     • If no passport, contact consulate for obtaining photo identification
     • Determine need for escort (family or friend), particularly if patient is very weak or has fluctuating level of consciousness
     • Encourage direct flights
     • Obtain flight information (airline, flight number, departure date and time)
     • Determine logistics of care and lodging when arrives in country of origin
     • Attempt to establish communication with local health care providers in country of origin (if available)
   o Obtain appropriate consultations
     • Physical therapy
       o Optimize strength, safe ambulation, energy efficiency
       o Caregiver teaching on safe transfers
       o Assess need for assistive devices (e.g., cane, walker, wheelchair)
       o Assess need for wheelchair transport in airport
     • Nutrition: convert continuous tube feeds to bolus tube feed regimen and provide necessary supplies and equipment
   o Assess need for oxygen and medical equipment
     • Determining Need for Oxygen
       o SpO2 on room air > 95% → oxygen not needed
       o SpO2 92-95% and no risk factors* → oxygen not required
       o SpO2 92-95% with additional risk factors* → needs oxygen in-flight
       o SpO2 < 92% → requires oxygen in-flight, possibly also on ground
     • *Risk factors
       • Hypercapnia
       • FEV1 < 50% predicted
       • Lung cancer
       • Restrictive lung disease involving the parenchyma(fibrosis), chest wall (kyphoscoliosis), or respiratory muscles
       • Cardiac disease
       • Within 6 weeks of exacerbation of chronic lung or cardiac disease
     • If oxygen required, arrange for portable oxygen tanks on each leg of flight
• Tracheostomy patients may need a portable, battery-powered suction machine (suitable for use with air travel)
  o Review medication regimen
    • Discontinue unnecessary medications
    • Convert all medications to oral or G-tube route

3. Medical clearance for commercial travel
  • Contact airline medical desk regarding medical clearance
    o Determine if airline requires specific medical form and discuss their ability to accommodate in-flight patient needs
  • Write letter to airline on hospital letterhead, include key information:
    o Patient name, airline and flight number, date and destination; name of traveling companion and relationship
    o Note if patient will have medications or liquid nutritional supplements s/he needs to take on board
    o Include contact information of physician
    o Describe your assessment of patient’s ability to tolerate travel
      ▪ Patient is stable for travel and can sit upright for the flight
      ▪ Can take own medications without assistance
      ▪ If external or indwelling urinary catheter present: Patient escort trained and has necessary equipment to manage the catheter
      ▪ Absence of airborne contagious illness (especially if jaundice present)
      ▪ Patient will not disrupt other passengers
    o Outline any equipment/assistance needs
      ▪ Requirements for oxygen (specify flow rate and if continuous (cannot exceed four L/min))
      ▪ Request wheelchair escort from curb to seat (and seat to curb), for comfort

4. Impending travel preparation
  • Obtain copies of medical records
    o Relevant laboratory, radiology, and pathology results
    o CD of important radiographs
    o Relevant clinical notes
    o Medication list, particularly noting bottles of liquid medications larger than 3 ounces
  • Order durable medical equipment, supplies as needed
    o Portable oxygen on ground (before, between, after flights); plan for return of oxygen tanks after patient boards plane
    o For tracheostomy patients: obtain portable, battery-operated suction machine authorized for use in air travel.
    o For patients with ostomies: obtain a supply of ostomy bags, adhesive, tape, gloves
    o For patients with other catheters/drains: obtain a supply of extra drainage bags
  • Provide adequate supply of medications
    o 30- or 90-day supply whenever possible provide written instructions in primary language
  • Ensure family brings clothing, including socks and shoes that fit (if edema) several days prior to travel
  • Ensure family has separate travel bag for medications and supplies, one-quart plastic Ziploc bag for medications
  • Patient and escort teaching, in patient's preferred language
    o Medication teaching, including symptom management during travel
    o Tracheostomy, ostomy, wound care, and/or catheter teaching, if needed
  • Finalize transportation plans
    o If patient leaving from hospital to airport, s/he should travel by car if possible, as reflects stability for travel
  • DAY BEFORE TRAVEL
    o Hold laxatives night before flight
    o Charge batteries on portable equipment
  • DAY OF TRAVEL
    o Ostomy secure and not leaking, if present
To limit need for ambulation, consider
  • Foley or condom catheter, with leg bag (Provide instructions for post-flight removal)
  • Give loperamide (if appropriate): one dose prior to leaving hospital and repeat every 4–6 hours until arrival in country of origin

5. Interventions when travel impossible or unsuccessful
  • Try to help facilitate visits from key family members, by writing letters to consulate, congressional representatives
  • Facilitate video calls with family
  • Encourage legacy work, memory making, photography

References:
Desire to return to country of origin -- before or after death -- "medical repatriation"

- **Include in goals of care discussion EARLY** -- educate pt/family on "window of opportunity"
  - recognize that goals/preferences may change as illness progresses
- Reasons patients may want to return
  - Desire to reunite with family
  - Available caregivers at home
  - Returning home and burial in home country may be culturally and religiously important; expense of returning alive vs. transporting remains
- Barriers
  - Cost
  - Physical or medical limitations to travel
- Considerations when preparing for international travel -- See separate checklist
- Ways to support patients, when return home isn't possible
  - Connection with loved ones (telephone, video conferencing, letters)
  - Facilitate visa requests (write letters to congressional representatives, embassies)
  - Discuss desire to return remains after death (and feasibility)
- Resources
  - Consulates and embassies can be incredibly helpful (even helping with repatriation costs, connection with local community)
  - Identify partners who can assist with care of undocumented migrants
    - Hospice agencies
    - Charities
  - Foundations and local grants/philanthropy can help with access to care issues
  - International Association of Hospice & Palliative Care – Resource directory
  - International pain management, opioid access
    - [http://www.treatthepain.org/](http://www.treatthepain.org/)

**References**