“Living Wills” and End of Life Care

University of Texas Health Science Center at San Antonio
South Texas Veterans Health Care System
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Objectives

• Discuss decisional capacity and surrogate decision making capacity
• Define Advance Care Planning and understand the implication of documenting Advance Directives
• Learn the common physiologic symptoms, signs & treatment approaches for patients near the end of their lives
• Become skilled at common family concerns on the days preceding death and be aware of comforting strategies
• Define death and describe how to pronounce a patient death
ON DEATH AND DYING....
Mrs. Flores is Dying...

• 78 year old woman with a two year history of breast cancer refractory to treatment (chemotherapy and radiation), which has now metastasized to her spine and lungs. Her functional status has been declining significantly over the past couple of months.

• Brought to the ER by daughter
  – Uncontrolled pain
  – Has not been getting out of bed
  – Dyspnea
Mrs. Flores is Dying...

Physical Exam:
Vitals: BP 70/40 HR 150 RR 30 T96.4
Caquectic, somnolent, ill-appearing, female
HEENT: temporal wasting
Lungs: Coarse breath sounds bilaterally with dullness R base
CV: Tachycardic regular
Extremities: 3+ edema to the knees
Assessment:
Mrs. Flores is terminally ill with metastatic breast cancer, not responsive to disease-modifying treatment
Who will be making decisions on behalf of Mrs. Flores?
What is Advance Care Planning (ACP)

• Process of planning for future medical care
• Empowers patient to explore own values, goals and document them
• Determine proxy decision-maker (voice)
• Proper documentation
Why Advanced Care Planning?

• 80% of people want to die at home – but only 20% do
• 50% are not able to make decisions about their care at the end of life
• Most doctors will treat if they don’t know a patient’s desires
• Family members often do not know a person’s wishes
Advance Care Planning Process

1. Reflect on those options and personal values
2. Conversation with loved ones & health care providers
3. Wishes and preferences are recorded
4. Life or preference changes?
ADVANCE DIRECTIVES

• Directive to Physicians, & Family or Surrogates

• Medical power of attorney

• out-of-hospital DNR order
Directive to Physicians, & Family or Surrogates

- Can be executed at any time
- Determined by patient quality of Life preferences
- **All** forms of medical intervention can be forgone if desired
Medical Power Of Attorney

- Allows a surrogate to speak for the patient
- Effective only when the patient is unable to speak for him/herself
- Supersedes the presumed chain of authority
- Good preventive health measure
Surrogate Decision Makers

If the patient is incapable of making medical decisions for themselves and they have no health care proxy, The following persons can act as surrogates:

1.actively involved spouse
2.actively involved adult child
3.actively involved parent or stepparent
4.actively involved adult sibling or
5.actively involved adult relative

Texas Administrative Code, rule §8.237 revised 2004
Out-of-Hospital Do Not Resuscitate Order (OOH DNR)

The OOH DNR program allows individuals to decide that they do not want to be resuscitated if they stop breathing and their heart stops beating.

Those resuscitative measures specifically listed in the OOH DNR legislation are cardiopulmonary resuscitation (CPR), advanced airway management, defibrillation, artificial ventilations, and transcutaneous cardiac pacing.
END OF LIFE CARE...
Why Last Hours Are Important

• 90% people die after a long period of illness with gradual deterioration until an active dying phase at the end

• Last hours of living provide opportunity to:
  – Finish business
  – Create final memories
  – Give final gifts
  – Find spiritual peace
  – Say good-bye
Managing The Dying Process

1. Unpredictability of Death
2. Creating the Setting for the Last Hours of Life
3. Physiological Changes and Symptom Management
4. Caregiver Preparation
5. When death occurs
Illness Trajectories

- Short Period Evident Decline (Cancer)
- Long term Limitations & intermittent serious Episodes (CHF, COPD)
- Prolonged dwindling Dementia, Frailty

Adapted from Murray, BMJ 2005
Progression of Symptom/Signs in the last two weeks of life

- Two semi-distinct stages over 1-14 days
- Difficult to prognosticate with precision within the last few days
- Time of high stress for family and caregivers
- Second guessing past decisions is common
- Most families are unfamiliar with the dying process—not sure what is “normal”
Early Stage

- Bed bound
- Loss of interest and ability to drink/eat
- Cognitive changes
- Increasing sedation; Lethargy
- Delirium: Hyperactive or Hypoactive
Late Stage

- Loss of swallowing reflex
- “Death rattle”
  - Pooled oral sections that are not cleared due to loss of swallowing reflex
- Coma
- Fever
- Altered respiratory pattern
- Skin color changes
- Death
An optimal care site has...

- Space for patient/family privacy
- Ready availability of medications and equipment to manage distressing symptoms
- Nursing support when needed
- Round-the-clock patient access for family, friends, caregivers
Site Options

• Home with hospice support
• Residential hospice
• Hospital: Inpatient hospice/palliative care unit
• Long-term care facility with hospice support
Last Hours Symptoms Differences Between Cancer and Non-Cancer Diagnoses

- **Cancer**
  - Pain 40-100%
  - Dyspnea 22-46%
  - More predictable dying trajectory

- **Non-Cancer**
  - Pain ~ 42%
  - Dyspnea ~ 62%
  - Less predictable dying trajectory

Morita 1998 Am. J. of Hospice & Pall Care
Symptoms-Signs of Approaching Death

- Functional decline
  - Loss of mobility: bed bound
- Decreasing oral intake
- Neurological Dysfunction
  - Decreasing cognition
  - Loss of swallowing reflex
- Pain
- Altered respiratory pattern
- Fever
- Skin color changes
Comfort needs near the end of life: “TOTAL PAIN”

• Physical Comfort (Physical pain): Pain, dyspnea, digestive complaints, fatigue, anorexia
  • Mental and Emotional Needs (Psychological pain): Anxiety, depression
  • Spiritual Issues (Spiritual pain): Finding meaning, hope, “unfinished business”
• Practical Tasks (Social pain): Small chores, finances, isolation

ABC of palliative care: Principles of palliative care and pain control
Bill O’Neill, Marie Fallon  BMJ 1997;315:801-804
Managing the Dying Process

General Treatment considerations

• Switch essential medications to non‐oral route
• Stop unnecessary medications/procedures
• Minimal vital signs monitoring
• Limit notification orders to those necessary
  – Frequent monitors can alarm patient/family
  – Numbers can distract family/staff from patient
Managing the Dying Process

• Evaluate for physical symptoms
  – Pain, dyspnea, urinary retention, agitation, secretions, etc.

• Evaluate for non-physical sources of suffering
  – Emotional: Delirium, depression or anxiety
  – Social: lack of financial or caregiving resources
  – Spiritual/ existential: loss of meaning

• Family
  – Contact, engage, and educate
  – Facilitate relationship with dying patient
  – Console
Cardiopulmonary Resuscitation Considerations

• **Resuscitation is not an effective end-of-life treatment**
  - Terminal process won’t allow physiologic circulation
  - 0% CPR survival to discharge in terminally ill patients *

• Enter DNR order
• At home complete out-of-Hospital DNR

**Terminology**
• DNR - *Do Not Resuscitate* – Implies that successful resuscitate is possible yet choosing not to do so
• Do Not Attempt Resuscitation (DNAR)
• Allow Natural Death (AND)

Resuscitation Statistics

• Most patients undergoing in-hospital cardiac resuscitation DO NOT SURVIVE to hospital discharge
• Pre-arrest variables associated with decreased survival include
  – homebound lifestyle
  – un-witnessed arrests
  – interval from admission and location (if hospitalized)
  – advanced age
  – advanced disease (cancer)

Application of the Decision Aid to the Validation Set of Attempted Resuscitations

The Patient Has a Chance of Hospital Discharge if Any of the Following Is True:

(A) The Arrest Was Witnessed

(B) The Initial Cardiac Rhythm Was Ventricular Tachycardia (VT) or Ventricular Fibrillation (VF)

(C) Pulse Was Regained During the First 10 Minutes of Chest Compressions

CPR OUTCOMES

• In general population  2-15 % survival
• Long Term Care 0-5% survival
• Unwitnessed arrest 0%
• Long Term survival  5%
• Public perception  48-85 % success
Function gradually declines in the days to weeks preceding death. Secondary to increased illness burden and diminished functional reserve

- Decreased tolerance for activities of daily living
- Bed bound
  - At risk for bed sores
Functional Decline Interventions

• Patient activity:
  – Allow patient to sit in chair if desired
  – Allow patient to use bedside commode if safe
  – Passive range of motion q 2hrs

• Patient/Family support:
  – Educate: normalize signs/ symptoms
  – Health aides or caregivers assist with ADLS
  – Durable medical equipment
    • Hospital Bed
    • Bedside commode
Decreasing Oral Intake

• All dying patients lose interest in oral intake in the days preceding death
  – Generalized weakness
  – Advance physiologic decline
    • Dysphagia in neurodegenerative illness
• Ketosis will blunt symptom of hunger
• Bedbound patient will not experience symptoms of postural hypotension
• No association between fluid intake and thirst in final days
When Oral Intake Is Reduced

Diet

• Liquid Diet
  – Fluids with salt: soup, sport drink help hydrate
  – Fluids with caffeine or free water are dehydrating (coffee, tea, colas)

• Remove dietary restrictions

• Let patient eat food of his choice
  – Family bought food OK if in the hospital

• Allow patient to sit up for meals; assist to eat
When The Patient Stops Taking Fluids

• Patients with fluid overload are not dehydrated (e.g. ascites or peripheral edema)
• Dehydration in last hours doesn’t cause distress
• Parenteral fluids generally not recommended
  – Worsen edema or ascites
  – Increase secretions (GI and respiratory)
  – Patient may need to be restrained if confused
  – If IV fluids are used, suggest a limited time trial
Decreased Oral Intake Interventions

• Meticulous oral care
  – Good hygiene
  – Moistening of the lips with petroleum Jelly to avoid cracking
  – Mouth cleaning and moisture with artificial saliva or baking soda mixture

• Caregiver Education
  – Do not force feed
  – Provide ice chips and small sips of liquid as tolerated
Non-oral Choices For Medications

Feeding Tube
• If already in place can be useful route for administering medications
  – Change essential medications to liquid
  – Some medications can be crushed

Rectal
• It may be inconvenient if other routes possible
• Available suppositories (e.g. acetaminophen) or can be compounded
• Caution if rectum is blocked by stool or tumor
Non-oral Choices For Medications

Intravenous (IV)
- Starting and maintaining may be difficult
- Not feasible in home setting
- If available provides reliable means of administering medications

Subcutaneous
- Small IV or butterfly needle inserted directly under the skin (abdomen or thigh)
- Allows injection small volumes of medicines
- Avoids burden of finding/maintaining IV assess
Non-Oral Choices for Medications

Transcutaneous
• Mucosas (oral, nasal)
• Specific formulations (e.g. Fentanyl)
• Transcutaneous use of IV or oral formulations

Transdermal
• Specific transdermal formulations
  – Fentanyl
  – Scopolamine
Question

Mrs. Flores is not eating and daughter thinks that you should do something so she doesn’t “starve to death”. On physical exam she is somnolent and has 3+ pitting edema which of the following are appropriate?

- Start IV fluids 125cc/hr for dehydration
- Provide meticulous oral care
- Educate caregiver about decrease in oral intake as a part of normal dying process
- Give Albumin IV to improve edema and bring fluid back to the vascular space
- Start total parenteral nutrition (TPN)
Neurologic dysfunction

- Decreasing level of consciousness
- Communication with the unconscious patient
- Terminal delirium
- Changes in respiration
- Loss of ability to swallow, sphincter control
Neurologic Dysfunction: Roads to Death

- Normal
- Sleepy
- Lethargic
- Obtunded
- Semicomatose
- Comatose
- Death
- Seizures
- Myoclonic jerks
- Mumbling Delirium
- Hallucinations

**THE USUAL ROAD 70-90%**

**THE DIFFICULT ROAD 10-30%**

Adapted from book Palliative Care Cores Skills and Competencies
Usual Road: Decreased Cognition

- Increased drowsiness
- Decreased ability to communicate
- Loss of swallowing ability
- Loss sphincter control
- Death

Caregiver Education

- Awareness > ability to respond
- Assume patient hears everything
Difficult Road: Terminal delirium

- Medical management
  - benzodiazepines
    - lorazepam, midazolam
  - neuroleptics
    - Haloperidol, chlorpromazine

- Seizures

- Family needs support, education
Mrs. Flores appears agitated, talking to her dead husband and having bugs crawling on her bed. Which one of the following is a recommended treatment for delirium in the last few days of life:

A. Anti-histaminic agent for sedation
B. Full work-up (laboratories, CxR, etc)
C. Empiric antibiotics
D. Short-acting benzodiazepine
Skin /Wound Care

Last hours focus is on comfort not healing

• Skin
  – Routine bathing to maintain hygiene
  – Moisturize skin
  – Protect fragile skin

• Wound care
  – Minimize frequency of dressing changes
  – Control infections with topical antibacterial/antifungal
  – Absorb odors
  – Masking odors: alternative smells
“Death Rattle”

Terminal syndrome characterized by retained oropharyngeal secretions caused by:

• Inability to swallow
• Lack of cough
• Multi-system shut-down

Which leads to loud noisy breathing
• Often very distressing to families
• Not always associated with dyspnea
“Death Rattle” Treatment

• Keep back of throat dry by turning head to side
• Discontinue artificial hydration/feedings
• Avoid deep suctioning
• Mouth Care
• Anticholinergic drugs to dry secretions
  o Scopolamine patch topical behind ear q3 days
  o Atropine eye drops 2-3 in mouth q4 hours or until patch effective
Question

After few hours, Mrs. Flores has been progressively more sleepy; She has now starting making a loud gurgling sound that has her daughter extremely concerned. The death rattle can best be managed by which of the following:

- A. Anti-cholinergic medication
- B. Deep suctioning
- C. Mechanical Ventilation
- D. Increasing fluids to loosen secretions
Pain management in Final Days: Patient With Significant Pain

- Assume that pain will continue to be present until death
- Do not discontinue opioids as mental status declines
- Stop sustained-release medicines and use immediate-release medications at this point
- ↓ Opioid dose for opioid toxicity e.g. myoclonus
- Diminished renal/hepatic function may need less opioid
- Judge analgesic need on physical signs
  - Grimacing and groaning; Tachycardia
- Use a trial of increased analgesics for suspected pain
- Use non-pharmacologic analgesics (e.g. music/massage)
Pain management in Final Days: The patient without significant pain

New severe pain due to the dying process is unlikely
Discomfort from lack of mobility can occur
Use a trial of analgesics for suspected pain
Caregiver education

- Normalize signs/symptoms
- Affirm the importance of family observations for potential pain
- Confirm the role of analgesics near end-of-life
  - Clarify confusion about opioid double-effect
  - Encourage non-pharmacological treatments
Palliative Sedation: Uncontrolled Symptoms

- Palliative sedation was defined as “deliberately lowering a patient's level of consciousness in the final stage of life,” and a symptom was considered refractory if “none of the conventional modes of treatment were effective or fast-acting enough, and/or if these modes of treatment were accompanied by unacceptable side-effects.”
Altered Respiratory Pattern

• Respiratory patterns in final days:
  – Increased or decreased rate or depth
  – Cheyne-Stokes breathing
  – Periods of apnea: death is likely within 24-48 hours

• Rapid breathing is often distressing for families/caregivers

• Treatment is only indicated for rapid breathing (30 resp/min)

• Careful titration of opioids can help control respiratory rate to a range of 10-20 breaths/min

• Use oxygen only if it appears to reduce distressing symptoms
Fever

- Fever is common 1-3 days prior to death
  - Aspiration pneumonia is likely etiology
- Most cases:
  - Scheduled acetaminophen (rectal if not taking PO)
- Refractory cases:
  - Cooling blankets
  - Parenteral NSAIDs or steroids
Skin Color Changes

A variety of changes may occur in the final hours to days before death:

- Vasoconstriction with cyanosis
- Mottling
- Ashen color
- Digital necrosis
- There is no specific treatment approach
Assisting Family

• Advise family about alerting other loved ones as to gravity of patient’s status

• Facilitate family presence
  – Order permission for family to visit or stay
  – Arrange visits for military and incarcerated relatives

• Enlist Pastoral Care and Social Work if appropriate
Coaching Families About Last Hours Changing Needs

<table>
<thead>
<tr>
<th>Sense /desire</th>
<th>Family loss</th>
<th>Coaching</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hunger</td>
<td>Nurturing</td>
<td>Other ways to nurture</td>
</tr>
<tr>
<td>Thirst</td>
<td>Nurturing</td>
<td>Mouth moist</td>
</tr>
<tr>
<td>Speech</td>
<td>Communication</td>
<td>Can still hear…</td>
</tr>
<tr>
<td>Vision</td>
<td>Being seen</td>
<td>May be conscious</td>
</tr>
<tr>
<td>Hearing</td>
<td>Being heard</td>
<td>Can still feel…</td>
</tr>
<tr>
<td>Touch</td>
<td>Physical presence</td>
<td>Transition to ‘non-physical’ relationship</td>
</tr>
</tbody>
</table>

Slide courtesy of Dr. James Hallenbeck
Things That Matter Most

"Please forgive me"
"I forgive you"
"Thank you"
"I love you"

... and goodbye

The Four Things That Matter Most
A Book About Living
by Ira Byock, M.D.
2004
# Signs of Impending Death

N=100 Cancer pts.

<table>
<thead>
<tr>
<th>Sign</th>
<th>Median time patient death</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respiratory Secretions (Death rattle)</td>
<td>23h (82h SD)</td>
</tr>
<tr>
<td>Respirations with mandibular movement</td>
<td>2.5h (18h SD)</td>
</tr>
<tr>
<td>Cyanosis/mottling</td>
<td>1.0h (11h SD)</td>
</tr>
<tr>
<td>Lack of radial pulse</td>
<td>1.0h (4.2h SD)</td>
</tr>
</tbody>
</table>

Morita 1998
Death

• Heartbeat/respirations Absent
• Pupils fixed
• Skin color appears yellow/waxen
• Body temperature drops
• Muscles relaxed
  – Jaw falls open
  – Eyes remain open
  – Sphincters relax
  – Body fluids may trickle
Death Pronouncement

• Death
  – not a difficult diagnosis no need for “pupil exam, assessment for pain”
  – Confirm death has occurred by absence of respirations and heartbeat

• Comfort family

• Complete necessary paperwork
  – Death note
  – Death certificate

• Communicate with medical examiner for selected cases

Hallenbeck, Palliative Care Perspectives
Death Pronouncement Skills

• *Anticipate* impending death and prepare family
• If called, inquire about circumstances
  – family present/not, anticipated/not
• If family present, assess ‘where they are’
  – Already grieving or need ritual to believe person died
• ‘Sacred silence’
• Console
• Next steps
• Self-care

Hallenbeck, JAMA May 2005
Telephone Notification of Death

• Avoid if possible
• Identify where recipient of news is (home, freeway etc.)
• Identify yourself and relation to the deceased
• Give brief ‘advance alert’:
  – I’m Sorry I have some sad news
• Slow recipient *DOWN*,
  – NOT – “you must come right in away”
• Identify contact person at hospital
  – “Ask for Dr. ... or Nurse ...”
• Empathetic statement

Hallenbeck, JAMA May 2005
Cultural Considerations

• Different cultures / religions have rituals surrounding time of death that should be accommodated if feasible
Question

Mrs. Flores has been receiving comfort care in a private room. You are called by nursing to pronounce Mrs. Flores’ death. Which of the following would be appropriate actions to take when pronouncing someone’s death (Select all that apply)

- Ask the family members to step out of the room
- Note absence of heartbeat
- Note absence of respiration
- Note absence of pain reflex by deep sternal rub or nipple pinching
Summary

• Death is a sacred moment in the life-cycle
• Families will remember a person’s death and how healthcare providers helped or not
• Healthcare providers can relieve the patients’ suffering and ensure a comfortable death
• The healthcare team can coach patients and families through their last hours of living
QUESTIONS?
210-617-5356
SANCHEZREILL@UTHSCSA.EDU
References

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- Emmanuel, Librach Palliative Care Cores Skills and Competencies 2007, chapter 19 Last Hours of Living (book)
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- Hallenbeck. Palliative Care in the Final Days of Life. JAMA 2005 Vol 293 No 18