Palliative Care at the Very End of Life

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Why Plan End of Life Care

“How people die remains in the memories of those who live on”.

Cicely Saunders
Like every birth, every death is unique

- Preparing for death is like preparing for birth
  - Unexpected events
  - Timing uncertain
  - What will be needed
  - What can we do to make it a “good” experience for patient, family and ourselves
Objectives...

- Describe the possibilities during the last hours of life for any dying patient.

- Describe assessments (physical, psychological, social, cultural, and spiritual) and interventions to improve care for imminently dying patients and their families.
Objectives

- Describe patient and family care at time of death and immediately following death.
Who Needs to be Prepared

- Family
- Friends
- Health Care Personnel
Where do people die

- Hospital - 50%
- Nursing Home - 25%
  - Hospice in nursing homes improves care of all residents
- Home - > 25%?
  - With hospice support - 50% Cancer patients
  - Without hospice support
Site of Death

- No “place” is best or worst to die

- Need to establish match between pt/family preferences and needs in order to have a “good death”
Common Causes of Death in Elders

- Dementias
  - Pneumonia
  - Urosepsis
  - End stage dementia
- End Stage Heart Disease
- End Stage Respiratory Disease
- Cancers
- End Stage Renal Disease
- Failure to Thrive
  - Dehydration
  - Malnutrition
Preparation for Death

What Type of Death

- **Expected** - Most deaths
  - Requests for assisted death
  - Prolonged “dying” phase

- **“Unexpected”** – minority of deaths
  - Happen quickly
  - Usually unexpected complications
  - Completely unrelated event
  - Suicide
What Is “Good Death”

- Definitions
  - Institute Of Medicine (1997)
  - Steinhauser et al. (2000)
“... people should be able to expect and achieve a decent or good death—one that is free from avoidable distress and suffering for patients, families, and caregivers: in general accord with patients’ and families’ wishes; and reasonably consistent with clinical, cultural, and ethical standards.” p. 4.
Steinhauser et al. 2000

- “...pain and symptom control, clear decision-making, preparation, completion, giving to others, and affirmation of the whole person”
Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT)

- Based on interviews with 3357 survivors
- 5 academic medical centers
- 40% of patients died in severe pain
- 55% were conscious
- 63% had difficulty tolerating symptoms
Improving Care in the Last 48 hours

- Carrying Out Advanced Directives
  - Living Will
  - DPOA-HC
Clinical Assessments and Interventions Needed

- Physiologic Changes
- Emotional
- Social
- Spiritual
Common symptoms that occur at the very end of life

- Pain / Discomfort
- Anxiety / Fear
- Dyspnea / Respiratory distress
- Restlessness / Muscle spasms
- Excessive secretions / Pulmonary edema
- Moaning / Agonal respirations
- Confusion / Delirium
- Nausea / Vomiting
Signs of Approaching Death: The Last 48 Hours

1. Reduced level of consciousness
2. Taking no fluids or only sips
3. No urine output or small amount of very dark urine (anuria or oliguria)
4. Progressing coldness and purple discoloration in legs and arms
5. Laborious breathing; periods of apnea; Cheyne-Stokes breathing
6. Bubbling sounds in throat and chest (death rattle)

(Blues & Zerwekh, 1984)
From Wilkie, 2002
Barriers to Recognize the Dying Process

- Denial—hope it gets better
- No definitive diagnosis
- Failure to recognize key symptoms
- Lack of knowledge of death trajectory
- Pursuing futile interventions

- Poor communication skills
- Ethical/Legal Concerns
  - about withholding or withdrawing treatment
  - of hastening death
  - about CPR
- Legal issues
- Cultural/spiritual practices
Overcoming Barriers

- Recognize key sign and symptoms
- Skilled communication of prognosis
- Team approach within your facility
- Know ethical & legal principles supporting care
- Appreciate cultural and religious traditions
Physiologic Changes During the Dying Process

- Increasing weakness, fatigue
- Decreasing appetite/fluid intake
- Decreasing blood perfusion
- Neurological dysfunction
- Pain
- Loss of ability to close eyes
Weakness/Fatigue

- Decreased ability to move
- Joint position fatigue
- Increased risk of pressure ulcers
- Increased need for care
  - ADLs
  - Turning, movement, massage
Decreasing Appetite/Food Intake, Wasting

- Fears
- Reminders
  - Food may be nauseating
  - Anorexia may be protective
  - Risk of aspiration
  - Clenched teeth express desires, control
  - Pulling out NG or G-tube
- Help family find alternative ways to care
Benefits and Burdens of Artificial Nutrition/Hydration

- Benefits of Artificial Nutrition/Hydration
  - Prolongs life if time is needed
  - May improve or forestall delirium
  - Maintains appearance of life giving sustenance
  - Maintains hope for future clinical improvement
  - Removal/avoidance of guilt by family members

Benefits and Burdens

- **Unproven** Benefits of Artificial Hydration
  - Improves quality of life
  - Improves survival across a population of dying patients
  - Improves symptom of thirst

Benefits and Burdens

- **Unproven** Benefits of Artificial Feeding
  - Reduction in aspiration pneumonia
  - Reduction in patient suffering
  - Reduction in infections or skin breakdown
  - Improves survival duration (in a population of similar patients)
Benefits and Burdens

- Burdens of Artificial Hydration
  - Maintaining parenteral access
  - Increased secretions, ascites, effusions, edema
  - Fuss factor: site care, IV bag changes
Benefits and Burdens

- Burdens of Artificial Feeding *
  - Risk of aspiration pneumonia is the same or greater than without non-oral feeding
  - Increased need to use restraints
  - Wound infections, abdominal pain and tube-related discomfort
  - Other tube problems
  - Cost; Indignity

* Much of this data comes from use of tube feeding in advanced dementia (see next slide)
Alternatives to Artificial Feeding/Hydration

- Allowing patient to eat/drink ad lib, even if aspiration risk is present

- No oral or non-oral nutrition/fluids
  - expectation that death will result in 14 days
  - Aggressive comfort measures will always provided
Summary of Benefits/Burdens

- Few medical benefits
- Substantial morbidity for patient
- But maybe positive psychological benefit for family
Decreasing Fluid Intake

- Fears: dehydration, thirst
- Remind family and caregivers
  - Dehydration does not cause distress
  - Dehydration may be protective
...Decreasing Fluid Intake

- Frequent mouth care
  - Swabs, artificial saliva
- Eye care
  - Saline drops
- Skin care
  - Frequent massage with lotions
Decreasing Blood Perfusion

- Tachycardia, hypotension
- Peripheral cooling, cyanosis
- Mottling of skin
- Diminished urine output
- Parenteral fluids will not reverse
Neurologic dysfunction

- Decreasing level of consciousness
- Communication with the unconscious patient
- Change in respiration
- Loss of ability to swallow, sphincter control
- Terminal delirium
Communication with the Unconscious Patient

- Distressing to the family
- Awareness > ability to respond
- Assume patient hears everything
...Communication with the Unconscious Patient

- Create familiar environment
- Include in conversation
- Assure presence and safety
- Give permission to die
- touch
Preparation for Death

- Consider how well your system deals with treatments of “last resort”
  - Voluntary stopping of eating and drinking
- Withdrawal of life support
  - Requests for assisted suicide
  - High dose pain management
  - Palliative sedation
Palliative Care Interventions: Sedation

• Use sedation for control of refractory symptoms in patients who are dying

• There is no evidence that sedation hastens death (Morita et al. 2001)

• Effective sedation can be achieved through the skilled, judicious use of a variety of medications including
  – Opioids
  – Barbiturates
  – Other
  – Benzodiazepines
  – Thiopental
Changes in Respiration...

- Altered breathing patterns
  - Diminished tidal volume
  - Apnea
  - Cheyne-Stokes respirations
  - Accessory muscle use
  - Last reflex breaths
...Changes in Respiration

- Fears
  - Suffocation

- Management
  - OPIOIDS!!! (Cochrane review-evidence strong)
  - Evaluate use of fans or fresh air
  - Position
  - Provide O₂ via nasal cannula
  - Treat anxiety from breathlessness
  - Treat “death rattle” as appropriate-Positioning, anticholinergics, do not deep suction-suction only oral secretions if helpful
Loss of Sphincter Control

- Incontinence of Urine
- Family needs knowledge and support
- Cleaning, skin care
- Urinary catheters
- Absorbent pads, surfaces
Pain

- Fear of increased pain
- Assessment of the unconscious patient
  - Persistent vs fleeting expression
  - Grimace or physiologic signs
  - Incident vs rest pain
  - Distinction from terminal delirium
Medications

- Limit essential medications
- Choose less invasive route of administration
  - Buccal mucosal oral first, then consider rectal
  - Subcutaneous, intravenous
  - Intramuscular almost never
As Expected Death Approaches

- Discuss
  - status of patient and realistic care goals
  - Role of all team members
- What the patient experiences, what onlookers see
As Expected Death Approaches

- Reinforce signs events of dying process
- Person, cultural, religious, rituals, funeral planning
- Family support throughout the process
Final Days to Hours

- Discontinue diagnostic tests
- Discontinue vital sign assessment
- Avoid unnecessary needle sticks
- Allow patient and family uninterrupted time together
- Ensure that family understands what to expect
- Ensure that caretakers understand and will honor advance directives
Emotional Symptoms

- anxiety/fear
- depression
Social Concerns

Patient Preference

- family vigil
- friends
- alone
Comfort Measures Only (CMO)

DNR
Review all diagnostics and treatments for contribution to comfort
Addresses Hunger & Thirst
Standardized Nursing Care
Symptom Management
Medications Ordered – PRN or Scheduled/Continuous
Spiritual Care

- Unfinished business
- Sacraments and other rituals
- Peaceful
- Awareness of Death
Uncommon Uncontrollable Events Prior to Death

Uncontrollable pain (when the pain was controlled prior to death)

Fatal Hemorrhage

Seizures

From Wilkie, 2002
Signs of Death

- Cessation of heart beat and respiration
- Pupils fixed and dilated
- No response to stimuli
- Eyelids open without blinking
- Decreasing body temperature
- Jaw relaxed and slightly open
- Body color is a waxen pallor

(From Wilkie 2002)
After Death Care: Various Cultural & Religious Groups

- Cultural and religious beliefs and practices are important to nursing care at the end-of-life and immediately after death

(From Wilkie 2002)
When you are called to pronounce a patient:

- Recognize the extreme emotional significance of the actual pronouncement of death to family members in room.
- Establish eye contact with family members(s) present.
- Introduce self to family.
PRONOUNCEMENT OF DEATH

• Examine patient for absence of breath sounds and heart sounds.

Note time of death.

After confirmation of death, acknowledge patients death to family if they are present and express condolences in a way that is comfortable for you.

Determine legal next-of-kin if family is not present

Ask legal next-of-kin about autopsy, organ/body donation, funeral home name (family can call it in later).
Pronouncing Death and Beyond

- Know and carry out cultural/religious rituals
- Know regulations (e.g., who can complete death certificate, etc.)
- Know funeral home
- Provide resources for family bereavement support
Summary

- Each death is unique experience and we are privileged to attend to dying patients.
- The memory of the dying experience (good and bad) remains with survivors.
- The quality of the hours and days prior to death can be influenced by early palliative care planning with patient & family, and staff and system preparations.
- Pathways and standards may influence and improve quality of dying.