Rafic Hariri School of Nursing &
The Salim El-Hoss Bioethics and Professionalism Program

PALLIATIVE & END-OF-LIFE CARE

Symptom Management at
End-of-Life

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Outline

- Prognosis
- Goals for the last hours of life
- Physical needs
- Psychological needs
- Spiritual needs
- Dignity
- Death
Prognosis -1-

“How long have I got?”

“Is he dying?”

“Is he going to last till the morning?”

“Her kids are abroad, should we tell them to come?”
Prognosis -2-

It is best to talk in terms of days or weeks or months as appropriate:

“When we see someone deteriorating from week to week we are often talking in terms of weeks; when that deterioration is from day to day then we are usually talking in terms of days, but everyone is different.”

(Watson et al., 2009)
Goals for the Last Hours of Life

- Ensuring comfort (physical, psychological, spiritual)

- Making the end-of-life experience as peaceful and dignified as possible

(Watson et al., 2009)
Physical Needs
Physical Needs

- Weakness and fatigue
- Loss of ability to close eyes
- Diminished oral intake
- Decreased blood perfusion
- Neurological changes
- Respiratory changes
- Swallowing impairment
- Loss of sphincter control
- Pain

Signs & symptoms of approaching death

(Emanuel et al., 1999)
Weakness & Fatigue

- Increased risk for pressure ulcers → Positioning every 2 hours, heels floating, hospital bed, air/water mattress...

- Increased dependence → Assist in activities of daily living, turning, moving, massaging...

Loss of Ability to Close Eyes

- Use lubricants, artificial tears, physiologic saline...

(Emanuel et al., 1999)
Diminished Oral Intake -1-

- Dying from starvation or thirst → Myth
- Anorexia and dehydration → Endorphin release → Sense of wellbeing
- Feeding → Does not improve symptoms or prolong life
- Enteral nutrition → Aspiration, vomiting...
- Parenteral nutrition → Fluid overload, pain at IV site, dyspnea...

(Emanuel et al., 1999)
Diminished Oral Intake -2-

- Allow the patient to eat whenever he/she wants
- Use subcutaneous infusions if need be. Up to 1.5L/day of 0.9%Saline (*most common*), 0.45%Saline, or Dext. and Saline.
- Ensure oral hygiene and moisture *e.g. use ice chips*
- Allow intake of essential medications only
- Use the least invasive routes of administration: Oral or buccal
  - Rectal (*e.g. morphine rectally*) → Subcutaneous and IV.
**DO NOT USE Intramuscular** (*pain, risk for bleeding*)

(Emanuel et al., 1999)
(Griffiths, 2012)
Decreased Blood Perfusion

- Tachycardia
- Hypotension
- Cyanosis
- Mottling of the skin
- Diminished urine output

Normal Findings, not reversed by parenteral fluids

(Emanuel et al., 1999)
Neurological Changes

- Decreased LOC → Communicate with patient even if not responsive

- Terminal delirium → Difficult road to death

- Confusion/agitation/restlessness → Distressing to patients and family

- Drugs of choice → Haloperidol (1st line) start with as low as 1mg and titrate as needed, Quetiapine (2nd line), Others: benzodiazepines

(Emanuel et al., 1999)
Respiratory Changes

- Altered breathing pattern: ↓ Tidal volume, apnea, Cheyne-Stokes breathing, accessory muscle use

- Distressing for family → Reassure that unconscious patients do not suffocate

- O₂ therapy → Prolongs dying process

(Emanuel et al., 1999)
Swallowing Impairment

- Loss of gag reflex → **Buildup of saliva in oropharynx**
  → **Terminal secretions (death rattle)**

- **DO NOT** suction → **Distress to patient and family**

- Postural drainage → **To prevent pooling of saliva**

- **Hyoscine butylbromide:** buccal, subcutaneous or IV if patient is conscious/semiconscious 20mg every 8 hours

- **Glycopyrrolate:** subcutaneous or IV if patient is unconscious. *Start with 0.2mg loading dose and titer PRN*

(Emanuel et al., 1999)
Loss of Sphincter Control

- Urinary/bowel incontinence → Distressing to patients and family

- Hygiene and skin care are paramount → Prevention of skin breakdown

- Assess for readiness to use diaper or urinary catheter before using either one of them

(Emanuel et al., 1999)
Pain

- **No evidence** that pain increases during dying process

- Pain in semiconscious/obtunded patients ➔ Look for tension across the forehead and between the eyebrows

- Knowledge about opiates is **paramount**

- Impaired liver and renal functions ➔ **Accumulation of metabolites** ➔ Need to lower doses of opiates

- Opiates with inactive metabolites: **Fentanyl**

(Emanuel et al., 1999)
Psychological Needs
Psychological Needs -1-

- Goals of care discussion → Cultural and religious constraints

- Instruct the family **NOT** to silent the patient when he/she talks about death

- Encourage them to listen to the patient’s wishes e.g. *preferred place of death, burial, goodbyes*...

(Watson et al., 2009)
Psychological Needs -2-

- Early referral to palliative care services to: Manage symptoms, tackle emotional distress, and deal with dependent children or vulnerable relatives

- Fears associated with symptoms “The pain will escalate to agony, breathing will stop if I fall asleep”

- Emotional distress “I am a burden to my family”

(Watson et al., 2009)
Psychological Needs -3-

- Past experience “Mr. X died suffocating, I don’t want to suffocate”

- Preferences about treatment or withholding treatment “What if nobody listens to me?”

- Fear from morphine “If I use morphine now, it won’t work when I really need it”

- Death and dying “I don’t fear death, but I worry about the dying process”

(Watson et al., 2009)
Spiritual Needs
Spiritual Needs

- Different religions and cultures deal with the dying process differently.

- **ASK!** It is paramount to address the patient and his/her caregiver beliefs.

- Offence is more likely to be caused by not asking than by asking i.e. *do you need a Cheikh? Would the help of “Abouna” bring comfort to you?*  

(Watson et al., 2009)
Dignity

“The state of being worthy of honor or respect”

- Mentioned in the Universal Declaration of Human Rights
- Maintain the patient’s dignity in a manner that is important to that particular patient
- What is dignified for one patient may not be for another

(Watson et al., 2009)
Death
As death approaches...

- No matter how well families are prepared, the prolonged dying process can be draining.

- Be available, offer clarifications, answer questions, and address concerns.

- Ensure comfort and reinforce the good job the family is doing e.g. you are doing great, you being next to him is a great thing...

(Emanuel et al., 1999)
Confirming Death

- Heart and breathing stop
- Pupils become fixed
- Body becomes pale and temperature drops
- Muscles and sphincters relax → Release of stools and urine
- Eyes may remain open → Close eyes
- Jaw can fall open → Close jaw with a piece of clothe or soft roll

(Emanuel et al., 1999)


Contact

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“Death is not extinguishing the light; it is putting out the lamp because the dawn has come”

- Rabindranath Tagore
Thank you