To prevent and relieve suffering, and promote quality of life at every stage of life
Disclosures

• The speaker has nothing to disclose.

• Exhibits coordinated through the Henry Jackson Foundation.

• Refreshments provided through the Henry Jackson Foundation.
The scope of the problem...

INTERNATIONAL
World Death Rate Holding Steady At 100 Percent
JANUARY 22, 1997 | ISSUE 31-02

GENEVA, SWITZERLAND—World Health Organization officials expressed disappointment Monday at the group's finding that, despite the enormous efforts of doctors, rescue workers and other medical professionals worldwide, the global death rate remains constant at 100 percent.

Death, a metabolic affliction causing total shutdown of all life functions, has long been considered humanity's number one health concern. Responsible for 100 percent of all recorded fatalities worldwide, the condition has no cure.

"I was really hoping, what with all those new radiology treatments, rescue helicopters, aerobics TV shows and what have you, that we might at least make a dent in it this year," WHO Director General Dr. Gernt Bladt said. "Unfortunately, it would appear that the death rate remains constant and total, as it has inviolably since the dawn of time."

Many are suggesting that the high mortality rate represents a massive failure on the part of the planet's health care workers.

"The inability of doctors and scientists to adequately address this issue of death is nothing less than a scandal," concerned parent Marcia Ggetto said. "Do you have any idea what a full-blown case of death looks like? Well, I do, and believe me, it's not pretty. In prolonged cases, total decomposition of the corpse is the result."

"What about the children?" the visibly moved Ggetto added.

"At this early date, I don't want to start making broad generalizations," Citizens for Safety's Robert Hemmlin said, "but it is beginning to seem possible that birth—as well as the subsequent life cycle that follows it—may be a serious safety risk for all those involved."

Death, experts say, affects not only the dead, but the non-dead as well.

http://www.theonion.com/content/news/world_death_rate_holding_steady_at
Objectives

• Define Palliative Care
• Describe common concerns or misconceptions
• Address these concerns with
  ▪ Principles of palliative care
  ▪ Ethical framework
Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual
Hospice Care

Presentation

Therapies to modify disease

End-of-life Care

6m Death

Bereavement Care
Hospice Palliative Care

Therapies to modify disease

End-of-life / Hospice Care

Presentation

Therapies to relieve suffering and / or improve quality of life

Hospice Palliative Care

6m Death

Bereavement Care
1. Disease management
- diagnosis
- date of diagnosis
- prognosis
- comorbidities

2. Physical issues
- pain, other symptoms
- level of consciousness
- function
- fluids, nutrition
- wounds

3. Psychological & cognitive issues
- anxiety
- delirium
- depression
- distress / emotions

4. Social issues
- family
- relationships, roles
- finances
- legal

5. Spiritual issues
- meaning, purpose
- existential beliefs
- hopes, expectations
- religion
- rites & rituals

6. Practical issues
- activities of daily living
  - personal care
  - household chores
- transportation
- caregiving

7. End of life/death management
- life closure
- legacy creation
- last hours of living

8. Loss, grief
- anticipated
- actual
- bereavement

Patient / family characteristics
- age, gender
- race
- culture
Ethics Template

- Medical indications
- Patient preferences
- Quality of life
- Contextual features
- Team dynamics

Common concerns

- Legally required to ‘do everything’?
- Is withdrawal & withholding therapies euthanasia?
- Does palliative care hasten death?
Palliative Medicine

• Relieve suffering
• Improve quality of living & dying

• Clinician intent supported by:
  ▪ Maximum benefit - Beneficence
  ▪ Minimal harm - Nonmaleficence
Principles Guiding Practice

- Autonomy
- Justice
- Agreement
- Durable decisions
- Truth-telling
- Informed consent
- Safe
- Legal
Withholding & Withdrawing

• Fluids & Nutrition at the End-of-Life
  ▪ Advantages / disadvantages of dehydration
  ▪ When are fluids indicated?
  ▪ Challenges in establishing goals of care & advance planning
“You’re KILLING her.”
“You’re STARVING her to death.”
Background . . .

1975 Karen Ann Quinlan
1983  Nancy Beth Cruzan
Legal Consensus

• 1990 Patient Self-Determination Act
• Right to refuse treatment
• Incompetent patients have same rights
• Substituted judgment, best interest
• Withholding = withdrawing
• Artificial nutrition and hydration are medical treatments

Meisel A. Kennedy Inst of Ethics J, 1993
# Life-sustaining treatments

- Resuscitation
- Elective intubation
- Surgery
- Dialysis
- Blood transfusions, blood products
- Diagnostic tests
- Artificial nutrition, hydration
- Antibiotics
- Other treatments
- Future hospital, ICU admissions
Role of the clinician . . .

• Help the patient and family
  Elucidate their values
  Understand the facts
  Dispel misconceptions
• Establish goals of care
• Facilitate decisions, reassess regularly
Role of the clinician

- Discuss alternatives
  - Including palliative and hospice care
- Document preferences, medical orders
- Involve, inform other team members
- Assure comfort, non-abandonment
Artificial Fluids & Nutrition

What is the medical evidence?
Enteral nutrition

- NG, PEG, J tubes
- Use GI tract
- Temporary inability to eat
- Neurological injury
- UGI mechanical obstruction
Effect of enteral nutrition on survival

• Higher mortality
  ▪ 50% dead at 12 months
  ▪ 60% dead at 18 months

• No reduction in aspiration

• No reduction in risk of pneumonia

• No evidence of better symptom control

Parenteral nutrition

- Intravenous (central line)
- No benefit in routine perioperative, ICU settings
- Benefit in prolonged GI tract toxicity
- Benefit in absence of GI tract function in otherwise healthy patient (short gut)

Effect of parenteral nutrition on survival

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<td>Tumor response</td>
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Evidence conclusion

- When cancer is the cause of the anorexia and weight loss, prospective randomized studies have failed to show benefit of artificial nutrition
- Gentle hydration may help some symptoms

Parenteral hydration

- Intravenous
- Subcutaneous (hypodermoclysis)
  - Equally efficacious, less risk, less skill, less cost
- Doesn’t relieve dry mouth
- Low volumes may help some symptoms

Bruera E. et al. JCO. 2005
Address misperceptions

- Cause of poor appetite, fatigue
- Relief of dry mouth
- Urine output
Clarify Terms

- Withholding
- Withdrawing
- Suicide
- Physician Assisted Suicide
- Euthanasia
Various religious views...
March 2004

“… the administration of water and food, even when provided by artificial means, always represents a natural means of preserving life, not a medical act.”
Catholic View

“There should be a presumption in favor of providing nutrition and hydration to all patients, including patients who require medically assisted nutrition and hydration, as long as this is of sufficient benefit to outweigh the burdens involved to the patient.”

“While medically assisted nutrition and hydration are not morally obligatory in certain cases, these forms of basic care should in principle be provided to all patients who need them, including patients diagnosed as being in a “persistent vegetative state” (PVS), because even the most severely debilitated and helpless patient retains the full dignity of a human person and must receive ordinary and proportionate care.”
Episcopal View

“... we must recognize that having a synthetic protein compound pumped directly into the intestine by skilled medical personnel is not the same as eating and drinking with friends.”

Cohen et al. Faithful living, faithful dying. 2000
Jewish View

“… withdrawal of life support and other interventions is generally not permissible… There may be certain exceptions to this, specifically in circumstances where the life support… is only serving as an impediment to the dying process…”

Kinzbrunner, BM. J of Palliative Medicine. 2004
Islamic View

“... the basic human rights of hydration, nutrition, nursing and pain relief cannot be withheld. These are ordinary life needs that are not to be categorized as treatment.”

Doka, KJ et al. Ethical Dilemmas at the End of Life. 2005
Be aware of your personal bias
Time-limited trials

- Warranted when unclear if it will achieve a specific goal
- Establish measure of success and time frame prior to start
- ‘Tolerating’ therapy is not a satisfying endpoint
Help family and staff

- Identify feelings, emotions, need ‘to do something’
- Identify other ways to demonstrate caring
  - Teach the skills they need
Discussing advance planning

- Stimulating meaningful conversation among ‘family’ members is most important
- Go Wish Cards
- POLST
- Advance Directives

Engelberg et al. JPSM. 2005
Menkin. JPM. 2007
Discussing hospice care

- Hospice care - present as a response to need vs. something to do when nothing left to do
- Elicit patient and family understanding of situation
- 10-15% of patients referred to hospice care disenroll (graduate)
Does this care hasten death?

- The principle of double effect!
  - Constipation with opioids
  - Pain control near end of life

- Preliminary evidence shows that this type of care actually prolongs life

Temel et al. NEJM. 2010
The standards of practice we create and the people we train will look after us when it’s our turn to receive care…

Are you ready?