

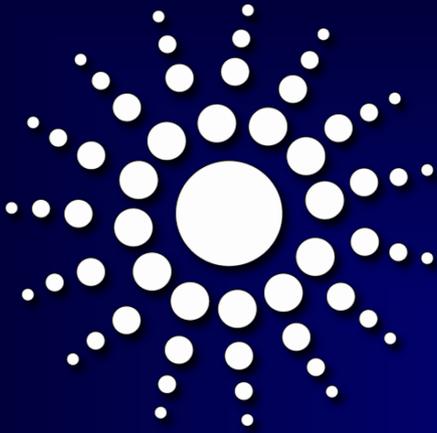
THE INSTITUTE FOR  
PALLIATIVE MEDICINE

*at San Diego Hospice*

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

The views expressed in this presentation are those of the author and do not necessarily reflect the official policy or position of the Department of the Navy, Department of Defense, or the United States Government.





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# ETHICAL OVERVIEW IN PALLIATIVE CARE

**Gary Buckholz, M.D.**

**Director, Palliative Medicine  
Fellowship Program**

# 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...

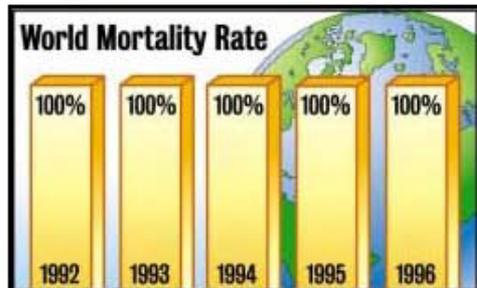
INTERNATIONAL

## 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.

ENLARGE IMAGE



Death rates since 1992

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. Gernst 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 Gretto 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 Gretto 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.

# 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

Therapies to  
modify disease

End-of-life  
Care

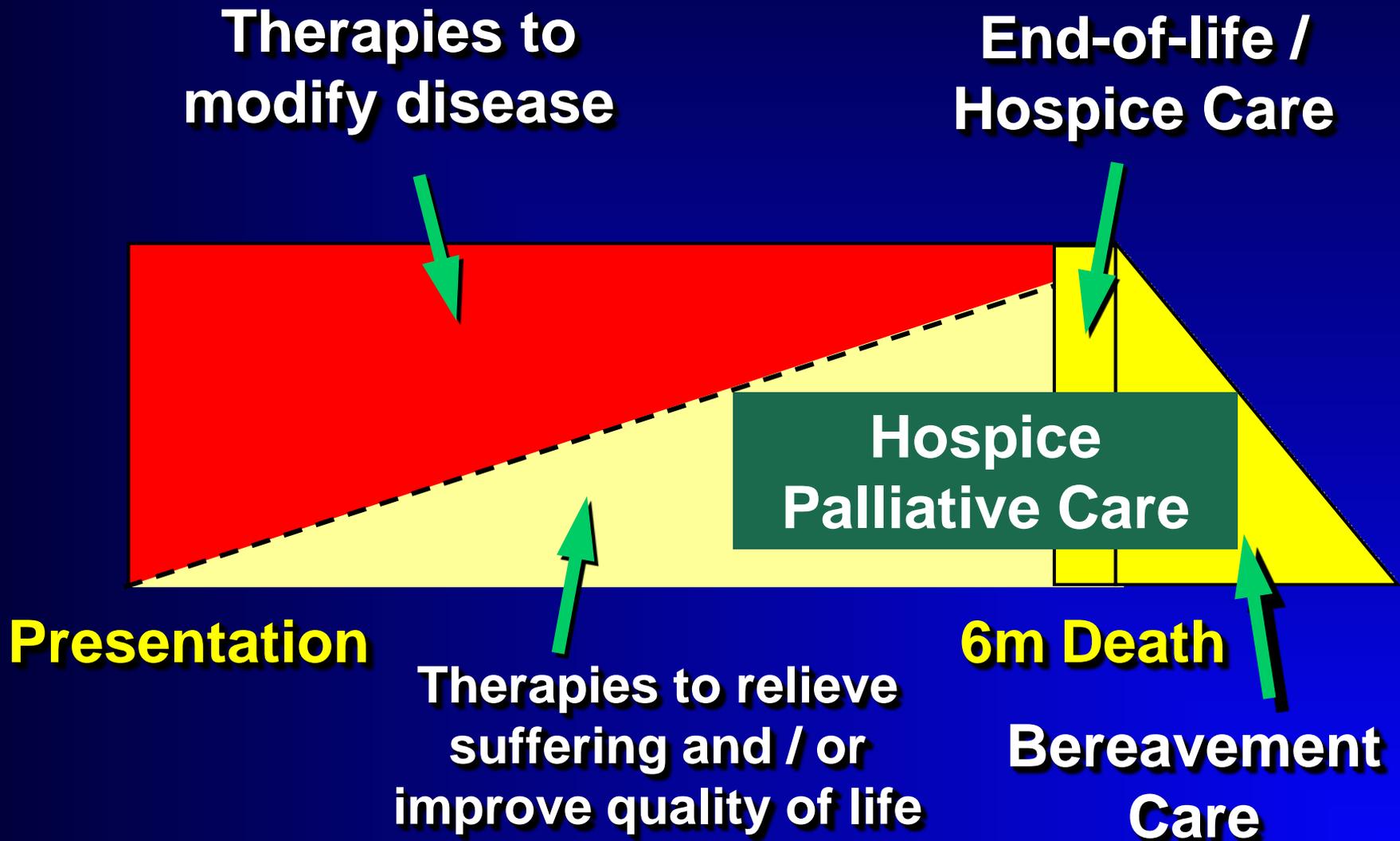


Presentation

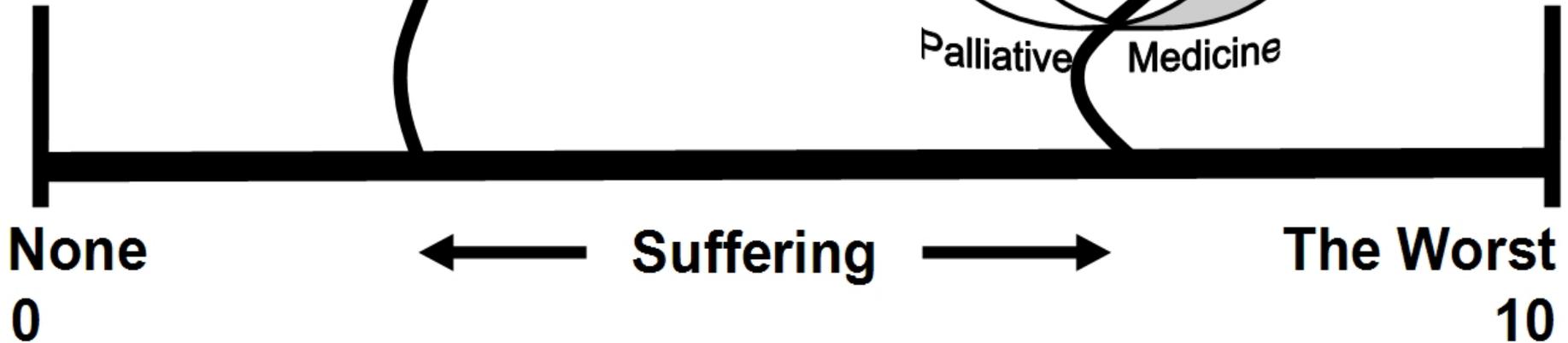
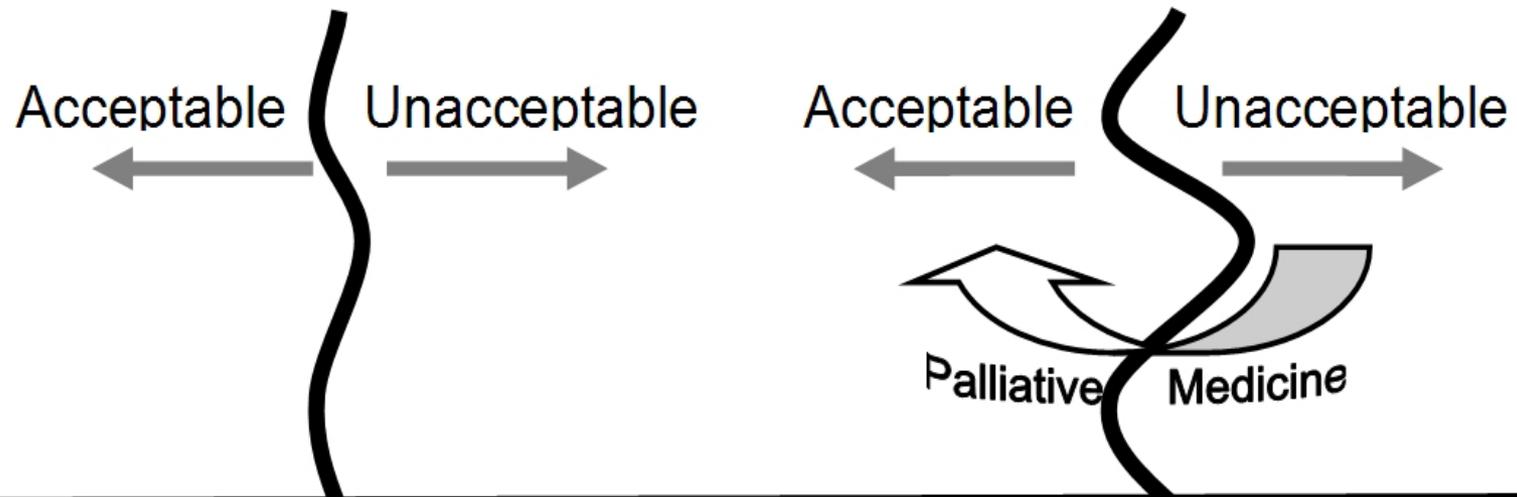
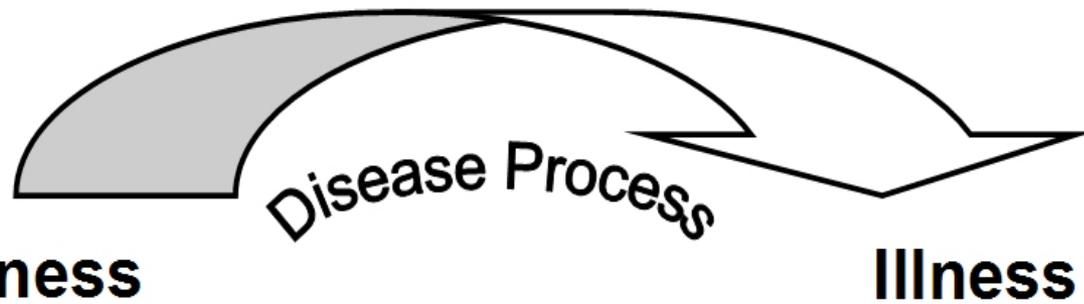
6m Death

Bereavement Care

# Hospice Palliative Care



# Change in Patient Status



## 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

## 8. Loss, grief

- anticipated
- actual
- bereavement

## Patient / family characteristics

- age, gender
- race
- culture

## 4. Social issues

- family
- relationships, roles
- finances
- legal

## 7. End of life/death management

- life closure
- legacy creation
- last hours of living

## 6. Practical issues

- activities of daily living
  - personal care
  - household chores
- transportation
- caregiving

## 5. Spiritual issues

- meaning, purpose
- existential beliefs
- hopes, expectations
- religion
- rites & rituals

# Ethics Template

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

Jonsen, Siegler and Winslade; *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine* (3rd edition McGraw-Hill 1992)

# 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**

# ... Background



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**

# 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

	Odds ratio
Control	1.00
Survival	0.81 p < 0.05
Tumor response	0.68

# 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

# Address misperceptions

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

# Clarify Terms

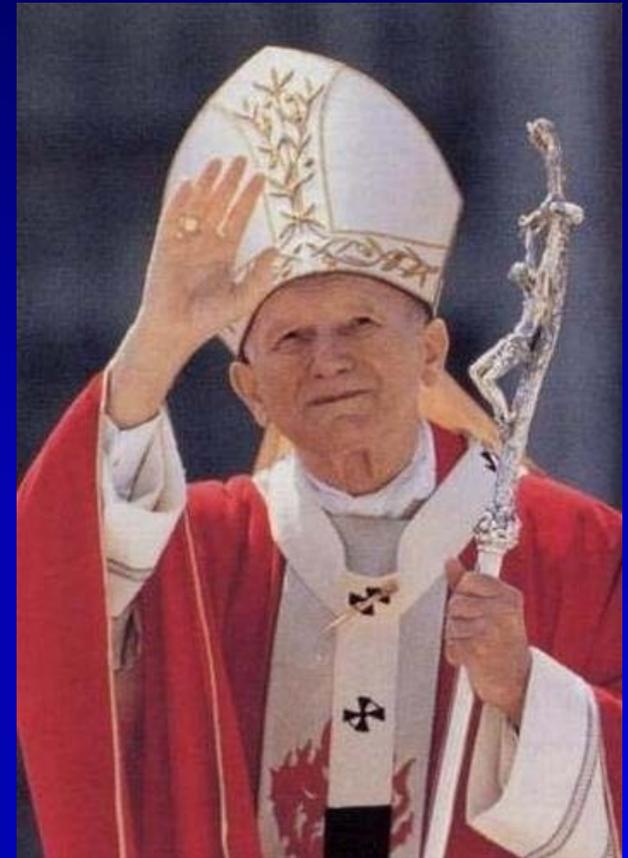
- **Withholding**
- **Withdrawing**
- **Suicide**
- **Physician Assisted Suicide**
- **Euthanasia**

**Various religious views...**

# Pope John Paul II

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.”**

# Catholic View

November 2009

**“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.”**

# **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...”**

# 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.”**

**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)

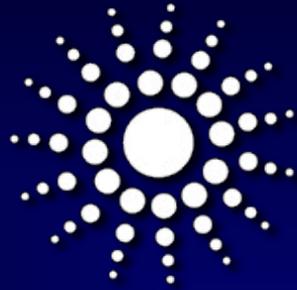
# Does this care hasten death?

- 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

**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?**



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