World Death Rate Holding Steady At 100 Percent

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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.

Lecture Overview

ILLNESS IN AMERICA
- Barriers to high quality end of life (EOL) care

PALLIATIVE CARE (PC)
- What is it?
- Epidemiology

HOSPICE CARE
- What is it? How does it compare to Palliative Care?
- Epidemiology

DEATH WITH DIGNITY
- What is it? How does it compare to Palliative Care?
- Epidemiology

OVERVIEW AND CLOSING
- Evidence for PC, Hospice
- Best practices
- Nurses role

Nurses Play a Major Role in Caring for Seriously Ill Patients and Their Families

- Elicit goals of care
- Assess, manage, coordinate care
- Listen
- Bear witness
- Communicate with team
- Knowledgeable in evidence-based practice

U.S. Deaths of All Ages Combined

1. Heart disease (611,105)
2. Malignant neoplasm (584,881)
3. Chronic lower Respiratory (149,205)
4. Unintentional injury/accidents (130,557)
5. Cerebrovascular (128,978)
6. Alzheimer’s (84,767)
7. Diabetes mellitus (75,578)
8. Influenza & pneumonia (56,979)
9. Nephritis (47,112)
10. Suicide (41,149)

CDC, 2015
**The Facts About Dying in America Today**

- 70% of those who die each year are 65 years of age or older
- Majority occur after a long, progressively debilitating chronic illness, such as
  - Cancer
  - Cardiac disease
  - Renal disease
  - Lung disease

**Illness/Dying Trajectories**

**Steady Decline, Short Terminal Phase**

**Illness/Dying Trajectories Sudden Death, Unexpected Cause**

**Illness/Dying Trajectories**

**Chronic Illness, Periodic Crises, Death**

**Illness/Dying Trajectories, Progressive Deterioration Expected Death**

**Serious Illness in America: It’s Impact on Care**

- 90M live with serious illness
- Exploding healthcare costs
- Poor understanding of prognosis
- Failure to treat pain and other symptoms
- Increased use of technology

Field & Cassel, 1997; Lunney et al., 2003; CPI, 2014; Meier, 2010; Munro, 2014
Suffering

- 30% of cancer patients report fair or poor health
- 58% have functional limitations
- Up to 90% have fatigue
- 33-5% have pain from the illness, its treatment or other co-morbidities
- Psychological distress ranges from 29-43%
- Caregiver and patient distress parallel each other and may be bidirectional

Institute of Medicine, Cancer Care for the Whole Patient, 2008.

Burdensome Transitions 2000-2009

- Deaths in acute care hospitals decreased from 32.6% to 24.6%
- Hospice use increased from 21.6% to 42.2%
- BUT...
  - Mean number of health care transitions in the last 90 days increased from 2.1 to 3.1
  - ICU use in the last month of life increased from 24.3% to 29.2%
  - 28.4% used hospice for 3 days or less and 40.3% of late hospice admissions were preceded by an ICU stay.


Toll of Death and Dying on Patients & Families/Caregivers

- Patients fear they will be a physical and financial burden
- If "nothing more can be done," will healthcare providers abandon them?
- How do families and caregivers adjust to role changes?
- Many drain life savings and/or go bankrupt to cover medical costs

Given et al., 2012

Overview of Caregivers: Their Commitment and The Cost

- Over 65.7 million adults provide unpaid care to sick/disabled adults
- Average of 20 hours a week
- Most are women in their mid/late 40s, working full-time
- 40% of women and 26% of men caregivers report emotional strain
- Cost of uncompensated care = $450 B/year

Family Caregiver Alliance, 2012; RAND, 2014

Barriers to Quality Care at the End of Life

- Failure to acknowledge the limits of medicine
- Workforce that is too small to meet demands
- Lack of training for healthcare providers
- Hospice/palliative care services are poorly understood
- Rules and regulations
- Denial of death
  - Failure to acknowledge the limits of medicine
  - Weeks, et al, found that 69% of lung cancer patients and 81% of colon cancer patients with stage IV disease did not report that their chemotherapy was not at all likely to cure their cancer
- Lack of payment models linked to quality measures


Changes Must Be Made: Development of Standards to Guide Practice

- Institute of Medicine
- National Consensus Project (NCP) for Quality Palliative Care
- National Quality Forum
- The Joint Commission

What Constitutes Good Quality Care At the End of Life?

- For Healthcare Teams: Providing symptom management and discussing emotional aspects of the disease
- For Patients: Achieving a sense of control, attaining spiritual peace, succeeding in having finances in order, strengthening relationships with loved ones, believing their life had meaning.

Grant & Dy, 2012; Jacobsen et al., 2011

NCP and NQF: 8 Domains of Palliative Care

- Structure and processes of care
- Physical aspects of care
- Psychological and psychiatric aspects of care
- Social aspects of care
- Spiritual, religious, and existential aspects of care
- Cultural aspects of care
- Care of the patient at the end of life
- Ethical and legal aspects of care

NCP, 2013

What is Palliative Care?

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. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient’s illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.


WHO Definition of Palliative Care

Palliative care:

- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

What is Palliative Care?

Palliative care means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.

Bridge Repair

Palliative care is specialized medical care for people with serious illnesses. It focuses on providing patients with relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a specially-trained team of doctors, nurses and other specialists who work together with a patient’s other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.

Characteristics of Palliative Care Philosophy and Delivery

- Interdisciplinary care
- Excellent communication between patients, families, healthcare providers
- Services provided concurrently with or independent of curative/life-prolonging care
- Hopes for peace and dignity are supported throughout the course of illness and pre-post dying process

Stop and Consider

Which of the following patients could benefit from palliative care?

A. 64-year-old with congestive heart failure, hypertension and diabetes
B. 32-year-old with acute myelogenous leukemia
C. 57-year-old with newly diagnosed amyotrophic lateral sclerosis
D. 76-year-old with Parkinson’s disease

Snapshot of Palliative Care in the US Today

- 90% of hospitals with 300 beds or more have palliative care teams
- 90% of Catholic-affiliated hospitals provide palliative care
- 96% of teaching hospitals have palliative care teams
- US southern states fall behind in providing palliative care
- 23% of for-profit hospitals provide palliative care

Prevalence of Palliative Care in US Hospitals: 2000-2011

http://getpalliativecare.org/whatis/
Core
Where is Palliative Care Provided and How is it Paid For?

- Palliative care is provided:
  - Hospital/Inpatient consult
  - Outpatient clinical setting
    - Free standing clinics
    - Embedded within specialty environments
  - “Home”

- Palliative care is paid for by:
  - Billing
  - Subsidies across departments
  - Philanthropy

Evidence: Quality of Life, Care and Outcomes

- More aggressive care at EOL is associated with poor QOL at death
  - Also associated with higher rates of caregiver regret, feeling unprepared for the death, major depressive disorder, and worse quality of life.

- Family members more likely to rate quality of care of hospice patients as “excellent”
  - 70.7% versus less than 50% of those dying in an institutional setting or with home health services (P=0.001).  

- A systematic review found PC improves pain and symptom control, mood and reduces hospital admissions.  

<table>
<thead>
<tr>
<th>Variable</th>
<th>Standard Care</th>
<th>Early Palliative Care</th>
<th>Difference between Early Palliative Care and Standard Care</th>
<th>P value</th>
<th>Effect size</th>
</tr>
</thead>
<tbody>
<tr>
<td>MCT score</td>
<td>7.1±1.5</td>
<td>7.8±1.3</td>
<td>0.7 (0.5-1.0)</td>
<td>0.03</td>
<td>0.42</td>
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<tr>
<td>LCS score</td>
<td>23.4±5.9</td>
<td>25.9±5.4</td>
<td>3.5 (1.6-5.4)</td>
<td>0.06</td>
<td>0.41</td>
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<tr>
<td>CSR score</td>
<td>13.5±2.1.5</td>
<td>15.8±2.1.5</td>
<td>2.3 (1.6-3.0)</td>
<td>0.008</td>
<td>0.52</td>
</tr>
</tbody>
</table>


5 Randomized Trials including Cancer Patients

- No harm in any trial
- Better patient understanding
- Improved satisfaction, communication
- More advance directives
- Better symptom control and quality of life
- Lower costs
- Higher quality of EOL care
  - Fewer readmissions, ED and ICU use; longer hospice LOS; increase in home death
- Better survival

Early Palliative Care for Lung Cancer

- Temel, et al: Bakitas ENABLE III phone based PC intervention
- Connor, et al: Mean survival was 29 days longer for hospice patients than for non-hospice patients
  - Statistically significant for CHF, lung and pancreatic cancer

Lengthening Life

<table>
<thead>
<tr>
<th>Variable</th>
<th>Standard Care</th>
<th>Early palliative care</th>
<th>Difference between Early palliative Care and Standard Care</th>
<th>P value</th>
<th>Effect size</th>
</tr>
</thead>
<tbody>
<tr>
<td>Survival</td>
<td>90.2%</td>
<td>92.4%</td>
<td>2.2%</td>
<td>0.007</td>
<td>0.56</td>
</tr>
</tbody>
</table>

Earlier Palliative Care Consults:
Larger Cost-Saving Effect

- Palliative care consult within 6 days of admission: Savings $1,312
- Palliative care consult within 2 days of admission: Savings $2,280
- This is equivalent to a 14% and 24% reduction, respectively, in the cost of hospital stay.

May et al., 2015

Costs

- PC patients discharged alive saved $1696 per admission (p=.004); PC patients who died saved $4908 per admission (p=.003)

- PC patients are significantly less likely to be admitted to ICU (p < 0.001)

- Medicare costs could be reduced for 70% of hospice recipients if used for a longer period


Cost Avoidance and Savings Associated with Palliative Care

- Different PC interventions, different populations but the outcomes tend to be similar across studies.

Primary Versus Specialty Palliative Care

- Primary palliative care is the care that each of you provide daily
  ➢ “The basic skills and competencies required of all physicians and other health care professionals.”

- Secondary palliative care
  ➢ Palliative care provided by board-certified palliative medicine physicians or other certified clinicians
  ➢ May include (e.g.):
    - More complex goals of care conversations, psychosocial dynamics and mood assessments
    - Legacy and bereavement counseling
    - Care of the imminently dying
    - Terminal extubation
    - Palliative sedation

- Tertiary palliative care
  ➢ “Care provided at tertiary medical centers where specialist knowledge for the most complex cases is researched, taught, and practiced.”


What is Hospice?

Hospice versus Palliative Care

- Palliative Care is the “umbrella” term
  ➢ Care can be provided at any point in illness – concurrent with aggressive and curative treatments

- Hospice is a subset of Palliative Care
  ➢ Interdisciplinary care provided in the last six months of life
    - Patient must forgo treatments with curative intent
**Hospice Care**

- In US, hospice is largely defined by the Medicare Hospice Benefit
  - Medicare pays for 84% of hospice recipients
  - 93% of hospices are Medicare-certified
    - 34% are not for-profit, 60% are for-profit, 5% government (federal, state or local)
    - "Volunteer" hospices


**Hospice Locations**

- 66.4% of hospice patients die at “home”
  - 97.1% of hospice patient care days were “routine home care” in 2011
    - Continuous home care (0.4%)
    - General inpatient care (2.2%)
    - Respite care (0.3%)
- Hospice can be provided in hospital, nursing home, adult family home, etc

**Hospice Includes:**

- Interdisciplinary care
  - Counseling
  - Spiritual care
  - Volunteer services
  - Bereavement services
- Medical appliances and supplies
- Drugs for symptom and pain relief
- Short-term inpatient, residential and/or respite care
- Homemaker/home health aide

**Primary Hospice Admission Diagnosis**

<table>
<thead>
<tr>
<th>Primary Diagnosis</th>
<th>2011</th>
<th>2010</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer</td>
<td>37%</td>
<td>36%</td>
</tr>
<tr>
<td>Non-Cancer Diagnoses</td>
<td>62.9%</td>
<td>64.4%</td>
</tr>
<tr>
<td>Delirium Unspecified</td>
<td>13.9%</td>
<td>13.0%</td>
</tr>
<tr>
<td>Dementia</td>
<td>13.3%</td>
<td>13.0%</td>
</tr>
<tr>
<td>Heart Disease</td>
<td>11.4%</td>
<td>10.3%</td>
</tr>
<tr>
<td>Lung Disease</td>
<td>8.9%</td>
<td>8.3%</td>
</tr>
<tr>
<td>Other</td>
<td>6.8%</td>
<td>5.6%</td>
</tr>
<tr>
<td>Stroke or CVA</td>
<td>4.1%</td>
<td>4.2%</td>
</tr>
<tr>
<td>Kidney Disease</td>
<td>2.7%</td>
<td>2.4%</td>
</tr>
<tr>
<td>Liver Disease</td>
<td>2.1%</td>
<td>1.9%</td>
</tr>
<tr>
<td>Non-AIDS/Neuro</td>
<td>1.0%</td>
<td>1.2%</td>
</tr>
<tr>
<td>Amyotrophic Lateral Sclerosis (ALS)</td>
<td>0.4%</td>
<td>0.4%</td>
</tr>
<tr>
<td>HIV/AIDS</td>
<td>0.2%</td>
<td>0.3%</td>
</tr>
</tbody>
</table>

National Hospice and Palliative Care, Facts and Figures on Hospice Care, 2012
What is Death with Dignity (DWD)?

- Allows physicians to prescribe a lethal dose of oral medication to a competent, adult patient with a terminal illness and life expectancy of 6 months or less
- Legal process with safeguards:
  - Includes written and oral patient requests and 15 day waiting period with an opportunity to rescind the request
  - Patient must self-administer the medication
  - Clinician confirms that the patient is competent, informed, and acting voluntarily
    - Clinician recommends the patient notify next of kin, have someone present at the ingestion and not take medication in a public place

DWD Nationally

- Oregon (1997) and Vermont (2013) have DWD laws
  - Vermont passed via the legislature
  - Montana?
- Neither palliative care, nor hospice
  - Single behavior/act within a larger context
  - Controversial due to ethical concerns

WA State DWD Participants

- Of all participants:
  - Most (77%) have cancer
  - 97% white, non-Hispanic
  - 52% married and 76% have some college education
  - 44% were 75 years or older
  - 91% cite loss of autonomy; 89% cite inability to engage in activities that make life enjoyable
- Of those who ingested medication in 2013:
  - 84% were at home
  - 86% were enrolled in hospice
SCCA Experience

- 114 individuals inquired about DWD between March 2009 and December 2011
- 44 (38.6%) did not pursue DWD
- 30 (26.3%) initiated but did not continue or died
  - 40 (35.1%) received the lethal prescription
    - 24 (60% of those receiving prescriptions, 21.1% of those inquiring) took the medication
    - 15.7% of all DWD participants in Washington state (N=255, 78% with cancer diagnoses)
    - Approximately 2% of all deaths state-wide and at SCCA during the same period

Overview

Current Practice of Palliative Care and Hospice

Quality-of-Life Model [http://prc.coh.org](http://prc.coh.org)

continuum of care

Prognostication

- Consists of 2 parts:
  - Foreseeing (estimating prognosis)
  - Foretelling (discussing prognosis)

- Performance status
  - Karnofsky – ECOG poor predictors, multiple symptoms, biological markers (e.g. albumin)
  - “Would I be surprised if this patient died in the next 6 months?”

Hui, 2011; Lynn et al., 2007
Hope for the Best...Prepare for the Worst

**Hope for the best**
- Review treatments that may prolong life and relieve suffering

**Prepare for the worst**
- What would be left undone?
- Who would make decisions if you could not make them?
- What would your wishes be regarding aggressive treatments, such as resuscitation?

What is a Good Death?

- Steinhauser identified 6 principles:
  - Pain and symptom management
  - Clear decision making
  - Preparation for death
  - Completion
  - Contributing to others
  - Affirmation of the whole person

Lessons Learned in Managing Barriers

- Give providers “the language”
- Build collaborative relationships with palliative care team
- Institute automatic triggers for palliative care consult

Role of the Nurse in Improving Palliative Care

- Maintaining a realistic perspective
  - Some things cannot be “fixed”
  - Focus on patient and family
- Use of therapeautic presence
- Facilitating communication and education
- Promoting multi and interdisciplinary care
  - Refer to palliative care or become a PC provider yourself
- Supporting your colleagues
Extending Palliative Care Across Settings

- Nurses as the constant
- Expanding the concept of healing
- Becoming educated
- Joint Commission Advanced Certification in Palliative Care

Final Thoughts.....

- Quality palliative care addresses quality-of-life concerns
- Increased nursing knowledge is essential
- “Being with”
- Importance of interdisciplinary approach to care

“... touching the dying, the poor, the lonely, and the unwanted according to the grace we have received, and let us not be ashamed or slow to do the humble work.”
-Mother Teresa

“You matter because you are you. You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but to live until you die”

Dame Cicely Saunders
Founder of St. Christopher's Hospice
London, England

Thank you!

Resources for Palliative Care

- Primer of Palliative Care
  ➢ AAHPM.org
- Hospice and Palliative Nursing Association (HPNA.org)
- Center to Advance Palliative Care (capc.org)
- Assessment Scales and other Tools
  ➢ City of Hope Pain & Palliative Care Resource Center (prc.coh.org)
- National Palliative Care Research Center
Resources for Supporting Conversations

- Aging with Dignity—Five Wishes, My Wishes, and Voicing My Choices
- Before I Die
- Community Conversations on Compassionate Care and Compassion and Support
- The Conversation Project
- Death Café
- Death Over Dinner
- DeathWise
- Engage with Grace
- Honoring Choices Minnesota
- Life Before Death: The Lien Foundation
- National Healthcare Decisions Day
- Project Compassion

Palliative Care at UWMC

- Cambia Palliative Care Center of Excellence
  - Director: Randy Curtis; Co-Director: Tony Back
  - See: https://depts.washington.edu/pallcntr/
- Palliative Care Services
  - UWMC
    - Lu Marchand, Medical Director for Inpatient Palliative Care, UWMC
    - Harborview
      - Inpatient service, Wayne McConrick and Tony Back
      - New inpatient PC services starting at Northwest and Valley
  - Long standing services at the VA (David Gruenwald) and Children’s (Ross Hayes)

Palliative Care at SCCA

- Charlie Pieterick, ARNP, ACHPN
- Molly Bumpus, ARNP, ACHPN
- Meagan Blazey, ARNP
- Judy Fihn, RN, CHPN
- Jodie David, RN
- Johanna Surla, RN
- Elizabeth Loggers, MD, PhD, Medical Director
- Moreen Shannon-Dudley, MSW, LCSW, MBA, Director of Supportive Care Services
- Petr Horak, Program Manager

Hospices Seattle Metro Area

- Non-profit
- Typically geographically distributed
  - Largest in the metro-area include:
    - Providence (King, Snohomish)
    - Evergreen (King, Snohomish)
    - Franciscan (King, Kitsap and Pierce counties)
    - Multi-Care/Good Samaritan (King, Pierce)
- In-patient (typically short stays of 5 days or less) hospice facilities
  - Evergreen
  - Franciscan
  - Hospice of Kitsap County
- There are no residential hospice facilities

Historical view...

- Middle Ages: Religious orders establish “hospices” at key crossroads on the way to religious shrines for pilgrims.
- 16th-18th Centuries: Religious orders care for the dying and destitute locally.
- 1800s: Madame Garinier of Lyon, France opens a “calvary” to care for the dying.
- 1879: Mother Mary Aikenhead, Irish Sisters of Charity, opens Our Lady’s Hospice in Dublin. William Munk, MD, writes “Euthanasia, or medical treatment in aid of easy death.”
- 1935-present: Interest grows in the psychosocial aspects of dying and bereavement, sparked by the work of Lindemann, Kubler-Ross, others.
- 1952: Mother Teresa opens first home for sick and dying, Nirmal Hriday (Pure Heart) in Calcutta.
- 1957-67: Cicely Saunders, works at St. Joseph’s Hospice, pioneered use of opioid analgesics given “by the clock”.
- 1965: Zelda Foster, SW at a Veterans Hospital wrote of the “conspiracy of silence” for inpatients facing death
- 1967: Saunders opens St. Christopher’s Hospice emphasizing multi-disciplinary care

More recently...

- 1980s: Hospice care, usually emphasizing home care, expands throughout the United States. Hospices begin to care for people with advanced AIDS.
- 1994: Medicare adds a hospice benefit.
- 1994: Project on Death in America (Open Society, George Soros)
- 1995: SUPPORT study
- 1997: Institute of Medicine (IOM): Approaching Death in America: Improving Care at the End of Life (Field & Cassel)
- 2001: IOM presented to 100 nurses in Pasadena, CA
- 2005: Last Acts, HRH national program which started in 2002, ends
- 2006: ASCO provisional clinical opinion recommending early palliative care for metastatic disease and any patient with a significant symptom burden
- 2014: IOM Report: Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life

Adapted from http://www.hospiceworld.org/history.htm