Philosophy and Principles of Palliative Care

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WHY SHOULD WE CARE?
What Do Patients with Serious Illness Want?

- Pain and symptom control
- Avoid inappropriate prolongation of the dying process
- Achieve a sense of control
- Relieve burdens on family
- Strengthen relationships with loved ones

- And, as death nears:
  - Preparation
  - Completion

What do they Say is Most Important at End of Life?

1. Freedom from pain
2. At peace with God
3. Presence of family
4. Being mentally aware
5. Treatment choices followed
6. Finances in order
7. Feeling life was meaningful
8. Resolved conflicts
9. Dying at home

Steinhauser et al. JAMA 2001;284:2476-82
What Do Family Caregivers Want?

475 family members, 1-2 years after bereavement:

- Loved one’s wishes honored
- Inclusion in decision processes
- Support and assistance at home
- Practical help (transportation, medicines, equipment)
- Personal care needs (bathing, feeding, toileting)
- Honest information
- 24/7 access
- To be listened to
- Privacy
- To be remembered and contacted after the death

Tolle et al. Oregon report card. 1999 www.ohsu.edu/ethics
What Do They Get?

From a mortality follow-back survey (n=1578), we learn they get **Not Enough**:

- Contact with MD: 78%
- Emotional support for patient: 51%
- Information about what to expect with dying: 50%
- Emotional support for family: 38%
- Help with pain/dyspnea: 19%

Caregivers Are At Risk

- Increased mortality (from MI/cardiac death)
  - RR 1.8 if caregiving > 9 hrs/wk for ill spouse
  - RR 1.6 among caregivers reporting emotional strain

- Care in ICU associated with 5x family risk of PTSD

- Care in hospital associated with 8.8x family risk of prolonged grief disorder

Lee et al. Am J Prev Med 2003;24:113
Schulz et al. JAMA 1999;282:2215
Wright, et al. JAMA 2008;300:1665-1673
Relationship Between Quality of Life and End-of-Life Care

EOL experiences by place of death

![Graph showing adjusted means for Quality of Life, Physical Comfort, and Psychological Well-Being across different places of death.]

- **Quality of Life**: Home with Hospice (6.6), Home (7.3), Hospital (5.3), Intensive Care Unit (5.0)
  - Significance: $P = .003$

- **Physical Comfort**: Home with Hospice (6.6), Home (5.9), Hospital (4.7), Intensive Care Unit (3.6)
  - Significance: $P < .0001$

- **Psychological Well-Being**: Home with Hospice (7.0), Home (6.0), Hospital (6.0), Intensive Care Unit (6.0)
  - Significance: $P = .02$

## End-of-Life Discussions Associated With Care Received

<table>
<thead>
<tr>
<th></th>
<th>No. (%)</th>
<th>Adjusted OR (95% Confidence Interval)&lt;sup&gt;a&lt;/sup&gt;</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total (N=332)</td>
<td>End-of-Life Discussion</td>
<td></td>
</tr>
<tr>
<td>Medical care received in the last week</td>
<td>332</td>
<td>123 (37.0) / 209 (63.0)</td>
<td></td>
</tr>
<tr>
<td>ICU admission</td>
<td>31 (9.3)</td>
<td>5 (4.1) / 26 (12.4)</td>
<td>0.35 (0.14-0.90)</td>
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<tr>
<td>Ventilator use</td>
<td>25 (7.5)</td>
<td>2 (1.6) / 23 (11.0)</td>
<td>0.26 (0.08-0.83)</td>
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<tr>
<td>Resuscitation</td>
<td>15 (4.5)</td>
<td>1 (0.8) / 14 (6.7)</td>
<td>0.16 (0.03-0.80)</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>19 (5.7)</td>
<td>5 (4.1) / 14 (6.7)</td>
<td>0.36 (0.13-1.03)</td>
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<tr>
<td>Feeding tube</td>
<td>26 (7.9)</td>
<td>11 (8.9) / 15 (7.3)</td>
<td>1.30 (0.55-3.10)</td>
</tr>
<tr>
<td>Outpatient hospice used</td>
<td>213 (64.4)</td>
<td>93 (76.2) / 120 (57.4)</td>
<td>1.50 (0.91-2.48)</td>
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<tr>
<td>Outpatient hospice ≥1 wk</td>
<td>173 (52.3)</td>
<td>80 (65.6) / 93 (44.5)</td>
<td>1.65 (1.04-2.63)</td>
</tr>
</tbody>
</table>

Abbreviation: ICU, intensive care unit; OR, odds ratio.<sup>a</sup>The propensity-score weighted sample was used for these analyses. Logistic regression models were also adjusted for patients’ treatment preferences, desire for prognostic information, and acceptance of terminal illness.

WHO ARE THE PATIENTS?
Chronic Illness Trajectories

Lunney JR et al. JAMA 2003;289(18):2387-92
Who Has Cancer, CHF, COPD?
Pathways Study

- 210 Patients enrolled
  - 70 Stage IV Breast, Colorectal, Lung or Prostate Cancer
  - 70 Class III-IV CHF with hospitalization in past year
  - 70 COPD with hypercapnea and ED visit

<table>
<thead>
<tr>
<th>Table 2</th>
<th>Self-Rated Health by Bed Days by Disease Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>Item</td>
<td>Descriptive Statistics</td>
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<tr>
<td>Poor or fair health with high number of bed days</td>
<td>Frequency</td>
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<td></td>
<td>Column %</td>
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<tr>
<td>Poor or fair health with low number of bed days</td>
<td>Frequency</td>
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<td>Column %</td>
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<tr>
<td>Good/excellent health with high number of bed days</td>
<td>Frequency</td>
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<td>Frequency</td>
</tr>
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<td></td>
<td>Column %</td>
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</table>

Steinhauser et al. J Pain Sympt Manage 2011;42(3):331-41
A final common pathway is shared by the sickest (and most vulnerable) 5-10%
WHAT IS THE FINANCIAL IMPACT OF THIS PROBLEM?
U.S. Health Spending as a Percentage of GDP

![Bar chart showing U.S. health spending as a percentage of GDP from 1960 to 2037. The chart indicates a steady increase from 5% in 1960 to 16% in 2005, with projected values of 19% in 2020 and 26% in 2037.](image-url)
The Sickest 10% account for 64% of spending

EXHIBIT 1

Percent of expenditures


Zuvekas S H, Cohen J W Health Aff 2007;26:249-257
Association Between Cost in Final Week of Life and Quality of Death (p=0.006)

WHAT IS PALLIATIVE CARE... 
...AND, CAN IT HELP?

Duke Medicine
Physical
- Pain due to disease location
- Other symptoms eg nausea
- Physical decline & Fatigue

Social
- Relationships with family/carers
- Role in family
- Work life
- Financial problems

Psychological
- Grief, Depression
- Anxiety, Anger
- Adjustment to condition

Spiritual
- Existential issues
- Religious faith
- Meaning of life and illness
- Personal value as a human being
What is Palliative Care?

• Specialized medical care for people with serious illness

• Relief from symptoms, pain and stress – *whatever the diagnosis*

• Improve quality of life for both patient and family

• A team that provides an *extra layer of support*

• Appropriate at any age and at any stage of illness
  – Can be provided together with curative treatment
Palliative Care Models

Diagnosis of Serious Illness

Old

End of Life

New

Life Prolonging Care

Hospice Care

Palliative Care

Bereavement
Providing Quality Care That Patients Want

• Vigorous Treatment of pain and other symptoms

• Relief from worry, anxiety and depression

• Close Communication about care

• Coordination of care and transitions

• Support for family caregivers

• A sense of Safety in the health care system
What is Palliative Medicine?

• The medical specialty delivering palliative care

• Recognized by the American Board of Medical Specialties (ABMS) since 2007

• Specialty certification sponsored by 10 boards, including Anesthesiology, OB/GYN, Radiology, and Surgery

• Currently, 2995 board-certified palliative medicine physicians in the United States
IS PALLIATIVE CARE BENEFICIAL?
Palliative Care

- Reduces symptom burden
- Improves patient and family satisfaction
- May increase survival
- Reduces costs
Mortality Follow-back Survey: Palliative Care vs. Usual Care

• N=524 family survivors

• Overall *satisfaction markedly superior* in palliative care group, p<.001

• Palliative care superior for:
  – emotional/spiritual support
  – information/communication
  – care at time of death
  – access to services in community
  – well-being/dignity
  – Care and setting concordant with patient preference
  – Pain
  – PTSD symptoms

RCT of Nurse-Led Telephone Palliative Care Intervention

• N= 322 advanced cancer patients in rural NH+VT
• Improved quality of life and less depression (p=.02)
• Trend towards reduced symptom intensity (p=.06)
• No difference in utilization

• Median survival:
  – intervention group 14 months
  – control group 8.5 months (p=.14)

Bakitas M et al. JAMA 2009;302(7):741-9
RCT Of Early Palliative Care Co-Management vs. Standard Cancer Care Alone

- N=151 newly diagnosed NSCLC
- Improved quality of life
- Reduced major depression (16% vs 38%; p=0.01)
- Reduced “aggressiveness” of care
  - Less chemo <14 days before death
  - More likely to enroll in hospice
  - Less likely to be hospitalized in last month

Early Palliative Care is Effective in Lung Cancer

Temel JS. NEJM 2010;363:733-42
# Hospital Palliative Care Reduces Costs

## Cost and ICU Outcomes Associated with Palliative Care Consultation in 8 U.S. Hospitals

<table>
<thead>
<tr>
<th></th>
<th>Live Discharges</th>
<th>Hospital Deaths</th>
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<tr>
<td>Costs</td>
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<tr>
<td>Per Day</td>
<td>$867</td>
<td>$1,515</td>
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<tr>
<td>Per Admission</td>
<td>$11,498</td>
<td>$23,521</td>
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<td>Laboratory</td>
<td>$1,160</td>
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<td>Pharmacy</td>
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<td>Imaging</td>
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<td>$1,656</td>
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<td>Died in ICU</td>
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<td>$18%</td>
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<table>
<thead>
<tr>
<th></th>
<th>Usual Care</th>
<th>Palliative Care</th>
<th>Δ</th>
<th>Usual Care</th>
<th>Palliative Care</th>
<th>Δ</th>
</tr>
</thead>
<tbody>
<tr>
<td>Per Day</td>
<td>$867</td>
<td>$684</td>
<td>$183*</td>
<td>$1,515</td>
<td>$1,069</td>
<td>$446*</td>
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<tr>
<td>Per Admission</td>
<td>$11,498</td>
<td>$9,992</td>
<td>$1,506*</td>
<td>$23,521</td>
<td>$16,831</td>
<td>$6,690*</td>
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<tr>
<td>Laboratory</td>
<td>$1,160</td>
<td>$833</td>
<td>$327*</td>
<td>$2,805</td>
<td>$1,772</td>
<td>$1,033*</td>
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<tr>
<td>ICU</td>
<td>$6,974</td>
<td>$1,726</td>
<td>$5,248*</td>
<td>$15,531</td>
<td>$7,755</td>
<td>$7,776***</td>
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<td>Pharmacy</td>
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<td>$186</td>
<td>$6,063</td>
<td>$3,622</td>
<td>$2,441**</td>
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<tr>
<td>Imaging</td>
<td>$851</td>
<td>$1,060</td>
<td>$208***</td>
<td>$1,656</td>
<td>$1,475</td>
<td>$181</td>
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<tr>
<td>Died in ICU</td>
<td></td>
<td></td>
<td></td>
<td>18%</td>
<td>4%</td>
<td>14%*</td>
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</table>

*p<.001  
**p<.01  
***p<.05

Average Total Hospital Costs Per Day for Patients Discharged Alive
How Palliative Care Reduces Length of Stay and Cost

• Clarifies goals of care with patients and families

• Helps families to select medical treatments and care settings that meet their goals

• Assists with decisions to leave the hospital, or to withhold or withdraw death-prolonging treatments that don’t help to meet goals
INTRODUCING PALLIATIVE CARE
The Good News: The Public has Never Heard about Palliative Care

Consumer Awareness About Palliative Care:
*How knowledgeable, if at all, are you about palliative care?*

- Not At All Knowledgeable: 70%
- Somewhat Knowledgeable: 14%
- Very Knowledgeable: 5%
- Don’t Know: 8%
- Knowledgeable: 3%

Source: *Data from a Public Opinion Strategies national survey of 800 adults age 18+ conducted June 5-8, 2011.*
Once Informed, Consumers are Positive

• 95% agree that it is important that patients and families be educated about palliative care

• 92% say they would like to consider palliative care for a loved one if they had a serious illness

• 92% say it is important that palliative care services be made available at all hospitals for patients with serious illness and their families
Words To Avoid

- “He failed therapy…”
- “It would be futile to….”
- “There’s nothing more to do…”
- “He’s not ready for palliative care…”

- Many people who need palliative care are not dying
- No one wants to die …. and most can’t accept the label until death is imminent
Introducing Palliative Care

• “Palliative care is specialized medical care that focuses on providing patients with relief from the symptoms, pain and stress of living with a serious illness. They provide an extra layer of support for our team.”
Summary

- Patients and families need more support
- More intensive care ≠ better care
- All patients with serious illness suffer equally
- Palliative care provides a model to treat suffering
- Palliative care is effective and saves money