Measuring and Improving the Quality of Dying and Death in End-of-Life Care

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UNC Program on Health Outcomes
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15:30-17:00

“Well, we've licked taxes—that just leaves death.”

“Well, how long do you want to live?”

“Unfortunately, there's no cure—they're not even a cure for a cure.”
Dying in the U.S.

- Only 25% of Americans die at home, although >70% say it is their wish
- More treatment may prolong dying; ICU treatment increasing
- We are a death denying and defying culture
- Hospice average length of stay dropped from 70 days in 1983 to 36

Last Acts Report

- National survey showed significant number of Americans, including those who have recently lost a loved one, are dissatisfied with the way the country’s health care system provides care to the dying.
- Out of those who recently lost someone close to them, 59 percent rate the American health care system’s care for the dying as being fair or poor.
- Those surveyed complained the most about the cost of end-of-life care: 49 percent of those who had lost someone rated the system as poor for its ability to insure that “families’ savings are not wiped out by end-of-life care.”

Last Acts Ratings of EOL in North Carolina

<table>
<thead>
<tr>
<th>Rating</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>State Pain Policies: 8 on 3-9 scale (2001)</td>
</tr>
<tr>
<td>E</td>
<td>Hospital EOL services: 85.4% with palliative care programs (2000)</td>
</tr>
<tr>
<td>B</td>
<td>- 14.3% with palliative care programs (2000)</td>
</tr>
<tr>
<td>C</td>
<td>- 18.9% deaths with hospice care (2000)</td>
</tr>
<tr>
<td>D</td>
<td>Pain in nursing homes: 40.4% (1999)</td>
</tr>
<tr>
<td>D</td>
<td>Palliative Care: Certified Clinicians: 0.19% (2000)</td>
</tr>
<tr>
<td>D</td>
<td>Location of death: 23.9% die at home (1999)</td>
</tr>
<tr>
<td>D</td>
<td>Advance Directives: 2 on 5 point scale (2002)</td>
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</tbody>
</table>

AARP North Carolina End of Life Care Survey

- 90% say total physical dependency would be worse than death; >70% unable to communicate or living in pain
- ¾ fear dying painfully; 71% concerned about being a burden on family
- ¾ would take pain meds only when pain severe; 1/3 fear becoming addicted to pain meds
- Honesty from doctors important
- 79% want to be off machines; ¾ have advance directives

Collaborators

- End of Life Care Program
  - J. Randall Curtis, Co-Director
  - Donald L. Patrick, Co-Director
  - Ruth A. Engelberg, Associate Director
  - Elizabeth Nielsen, Program Manager

- Life’s End Institute; Missoula Demonstration Project
  - Ira Byock (now at Dartmouth)

- ICU Team and Hope Study
  - Marjorie Wennick, Mark Tornell, Gordon Rubenthal, Tony Back, Lisa Virg, Lynne Robins, Barbara McGrath, Sarah Shannon

- CAM at End of Life
  - Bill Lafferty, Leona Standish

- Other users:
  - Wendi Norris, David Au at UW
  - Rich Maturoski, Linda Ganzini Oregon Health Sciences
  - Wes Ely, Gari Levy, VanderbilU
End of Life Research and Practice

Goals

- Develop and disseminate measures and information systems on the quality of:
  - dying and death
  - communication about end of life
  - end-of-life care
- Develop and disseminate evidence-based interventions to improve the quality of end-of-life care

Value Critical Statement

- How we define the problem?
- Whose interests are served?
- Who are the stakeholders?

Measuring quality of death

Is measuring QODD the ultimate form of reductionism?

‘Is death only a negative number in our combat readiness or population totals? Or is it a major intellectual and emotional loss? How will our species prosper if we treat ourselves according to numerical facts, as no more than arithmetic?’

— AL Kennedy in *Original Bliss*

I am looking forward to becoming humus myself buried naked without coffin under a tree on my land in Ao Tea Roa

Hundertwasser
b 15 December 1928 Wien
d 19 February 2000 Aboard QEII

Our lives can be prolonged by physicians not one day, we live as long as God has decided. But there is a great difference whether we live miserably, like poor dogs, or well and healthy; a clever doctor can do a lot in that respect.

Johann Wolfgang von Goethe, conversation with F. von Muller, August 12, 1827.
Three Distinct Concepts?

- Quality of care
- Quality of life at the end of life
- Quality of dying and death

Personal Research and Teaching

- Teaching dying and death at St. Thomas’s Hospital to medical students mid ’70s
- Qualitative study in cancer with Russ Harris (UNC)
- Work with Marion Danis on ICU and treatment preferences in nursing homes (UNC)
- Work with Richard Uhlmann, Bob Pearlman and team at UW on states worse than death and treatment preferences
- IOM Committee on End-of-Life Care
- Co-direct EOL Research program with Randy Curtis at UW

Influential Prior Research

- United Kingdom National Surveys, 1967, 1989
- SUPPORT and ICU
- Research on validity of retrospective reports
- Research on “a good death”

A Quality Death: IOM Definition

*a death that is free from avoidable distress and suffering for patients and their families, in accordance with the patients’ and families’ wishes, and reasonably consistent with clinical, cultural, and ethical standards*

Field M and Cassell C (eds.) (eds.)

Other Issues

- Emphasis on life events and dying as matter of personal choice
- Preferences for life-sustaining treatment
- Intrusiveness of pre-death and post-death interviews

Crossing the Quality Chasm in End of Life Care

- Care based on continuous healing relationships
- Customization based on patient needs and values
- The patient as the source of control
- Shared knowledge and the free flow of information
- Evidence-based decision making
- The need for transparency
- Anticipation of needs
- Cooperation among clinicians
- Coordination among caregivers, patients, families

**Operational Definition of QODD**

...degree to which a person’s preferences for dying and the moment of death agree with observations of how the person actually died as reported by others. Level of agreement must be modified by unavoidable circumstances surrounding death that may have prevented the realization of patient prior preferences.

*Patrick DL et al. JPSM 22 (3):717–726, 2001*

**Conceptual Model for Measuring the Quality of Dying and Death**

Stewart A. et al. JPSM 1999

- **Patient Factors**
  - Affecting Health Care and Outcomes of Care
- **Structure and Process of Care**
- **Outcomes of Care**
  - Satisfaction with Health
  - Quality and Length of Life

**Development of the QODD**

- **Review of the literature**
  - Quality of life at the end of life
  - Symptom assessment scales
  - Quality of care at the end of life
- **Qualitative research with**
  - AIDS, COPD, cancer, well older adults, stroke, nursing home, hospice
- **All research begins and ends with the qualitative**

*Patrick DL et al. JPSM 22 (3):717–726, 2001*

**QODD Instrument**

- Comprised of 31 items, administered to loved one after death (within 3 months)
- Question stem: “How would you rate this aspect of [patient name]’s dying experience?”
- Each item on scale from 0 to 10
  - 0 = terrible experience
  - 10 = almost perfect experience
- Total score ranges from 0 – 100

*Patrick DL et al. JPSM 22 (3):717–726, 2001*

**Hypothesized QODD Domains**

- Symptoms and personal care (6)
- Preparation for dying and death (13)
- Family (5)
- Treatment preferences (4)
- Whole person concerns (3)

*Patrick DL et al. JPSM 22 (3):717–726, 2001*
Examples: QODD Domains

- Symptoms and personal care
  - Having pain under control
- Preparation for dying and death
  - Feeling at peace with dying
- Family
  - Spending time with children
- Treatment preferences
  - Having discussed end of life wishes with physician
- Whole person concerns
  - Finding meaning and purpose in life

Current Studies Using QODD

- Missoula Demo Project (n=205)
  - sample of all deaths in Missoula County in 1996 and 1997
- Hospice Study (n=93)
  - sample of patients in 2 Seattle hospices
  - 62 patients with QODD data
- COPD Study (n=115)
  - sample of patients with COPD on home O2

End of Life’s Institute: Missoula Demonstration Project

- Identified all deaths in Missoula County in 1996-7 using funeral records
- Telephone person listed as “primary contact” requesting interview
- Study personnel did in person interview with 1 person per decedent
- Average time between death and interview: 708 days

QODD Score and Patient Characteristics

- QODD scores were NOT associated with
  - Patient age
  - Patient gender
  - Patient race (white vs. non-white)
  - Patient education
  - Household income

Missoula Study Results

- Higher QODD Associated With
  - MD/Nurse “could have done more”
  - Discussed dying and death with loved one
  - Preferences for medical care followed during last week
  - Lower symptom burden and fewer invasive treatments
  - Better communication from health care team
  - Single physician primarily responsible for care
  - Availability of familiar team member at night
  - Comforting religious experiences

**Hospice Sample Descriptives**

<table>
<thead>
<tr>
<th></th>
<th>Patients (n=92)</th>
<th>Loved Ones (n=92)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (mean and sd)</td>
<td>71 (14)</td>
<td>58 (15)</td>
</tr>
<tr>
<td>% Female (n)</td>
<td>59 (55)</td>
<td>66 (61)</td>
</tr>
<tr>
<td>% White (n)</td>
<td>95 (88)</td>
<td>91 (85)</td>
</tr>
<tr>
<td>% Married (n)</td>
<td>48 (45)</td>
<td></td>
</tr>
<tr>
<td>% College educated (n)</td>
<td>24 (22)</td>
<td>28 (27)</td>
</tr>
<tr>
<td>Income</td>
<td></td>
<td></td>
</tr>
<tr>
<td>% &lt;= $12,000</td>
<td>22 (20)</td>
<td></td>
</tr>
<tr>
<td>% &gt; $12,000, &lt;=$36,000</td>
<td>46 (43)</td>
<td></td>
</tr>
<tr>
<td>% &gt; $36,000</td>
<td>24 (22)</td>
<td></td>
</tr>
</tbody>
</table>

**PADD: Preferences About Dying and Death Administered Prior to Death**

- Comprised of same 31 items as QODD
- Question stem: “Imagine the last seven days of your life. How important would it be to you to...”
- Each item on scale from 0 to 10
  - 0 = not at all important
  - 10 = extremely important
- Total score ranges from 0 – 100
- Respondents rated “top five” from all items endorsed with a “10”.

**Agreement Between Patient and Loved One Prior to Death**

- Data from Hospice Study N=62
- Ranged from 25.0% for “spending time alone” to 83.9% for “spending time with spouse”.
- On 11 of the 30 items (37%), patients’ and their loved ones’ ratings agreed 60% of the time or more and all domains represented.

**Correlates of Agreement**

- Shared residence between patient and loved one
- Discussions about preferences have taken place

**QODD Scores Using Pre-Death Preferences**

<table>
<thead>
<tr>
<th></th>
<th>Total QODD</th>
<th>QODD for Items =&gt;8</th>
<th>QODD for Items=10</th>
<th>QODD for “Top Five”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean (SD)</td>
<td>75 (12)</td>
<td>74 (14)</td>
<td>76 (14)</td>
<td>73 (18)</td>
</tr>
<tr>
<td>Range</td>
<td>45-100</td>
<td>48-100</td>
<td>48-100</td>
<td>28-100</td>
</tr>
</tbody>
</table>

**Loved Ones Assessment of Quality of Care and the QODD after Death**

<table>
<thead>
<tr>
<th></th>
<th>Total QODD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rating of quality of care from all health care professionals.</td>
<td>0.41 (.002) n=56</td>
</tr>
<tr>
<td>Rating of quality of care from physician.</td>
<td>0.34 (.01) n=55</td>
</tr>
<tr>
<td>Extent to which patients’ treatment plans were followed.</td>
<td>0.42 (.000) n=53</td>
</tr>
<tr>
<td>How often health care professionals explained treatments.</td>
<td>0.33 (.02) n=51</td>
</tr>
</tbody>
</table>
Hospice Study Summary

- Pre-death importance ratings did not change after-death QODD scores.
- Higher income and higher functional status prior to death associated with better QODD.
- Pre-death quality of care ratings not associated with QODD.
- After-death quality of care ratings are associated with better QODD.

Methodological Issues

- Recruitment major barrier to research (bias).
- Assessment at end-of-life difficult, particularly in weeks and days just prior to death.
- Who is best reporter after death?
- Response shift and what to do about it?
- Dynamic versus static assessments.
- Finding determinants of high quality dying, i.e., spirituality, economic resources, values.

Methodological Issues (cont.)

- Organizational context important to investigate.
- Processes of care difficult to link; which are most important.
- If you are happy with your care, is your QODD better? What is direction between satisfaction and evaluating dying?

How to improve the quality of dying

- Improve communication between patient and loved ones and between patients and providers.
- Improve pain & symptom management.
- Ease financial burden on family.
- Increase continuity of care:
  - evening/weekend coverage
  - primary MD responsible for care
  - Increase access to care coordinator
  - Increase access to spiritual resources.

Improving Symptom Management: Chairing an NIH Consensus Panel

NIH State-of-the-Science Conference on Symptom Management in Cancer: Pain, Depression and Fatigue
July 15-17, 2002
http://consensus.nih.gov/ta/022/022_statement.htm
Conclusions of Panel

- Too many cancer patients receive inadequate treatment for their symptoms.
- Clinicians should use brief assessment tools routinely to initiate evidence-based treatments.
- Current evidence to support the concept of cancer symptom clusters is insufficient.
- Research needed on the definition, occurrence, assessment, and treatment of pain, depression, and fatigue alone and together.
- Fear of cancer and its consequences must be ameliorated.
- The state of the science in cancer symptom management should be reassessed periodically.

Outcomes Research in Improving Dying and Death

- Monitor wishes and outcomes
- Evaluate delivery systems and arrangements
- CQI: Plan, Do, Study, Act
- More qualitative research academic and market
- Use in training for providers and patients
- Keep attention on local initiatives
- Increase diversity in populations—homeless, ethnic groups and act on cultural variation

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Once dead, the dead don’t care. The living have to live with it. You don’t. There’s the pain and the pleasure of memory. There’s the invoice for services rendered and there’s the check in the mail for its payment. Once you are dead, put your feet up, call it a day, and let the husband or missus or the kids or a sibling decide whether you are to be buried or burned or blown out of a cannon or left to dry out in a ditch somewhere. It’s not your day to watch it, because the dead don’t care.