Should we be measuring the quality of end-of-life care?

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Why we measure quality

• Internal benchmarking
• Inform quality improvement
• Pay-for-performance and public reporting
Intensive care unit quality improvement: A “how-to” guide for the interdisciplinary team*

J. Randall Curtis, MD, MPH; Deborah J. Cook, MD; Richard J. Wall, MD, MPH; Derek C. Angus, MD, MPH, FRCP; Julian Bion, FRCP, FRCA, MD; Robert Kacmarek, PhD, RRT; Sandra L. Kane-Gill, PharmD, MSc; Karin T. Kirchhoff, RN, PhD, FAAN; Mitchell Levy, MD; Pamela H. Mitchell, PhD, CNRN; Rui Moreno, MD, PhD; Peter Pronovost, MD, PhD; Kathleen Puntillo RN, DNSc, FAAN

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American Thoracic Society Documents

An Official American Thoracic Society Policy Statement: Pay-for-Performance in Pulmonary, Critical Care, and Sleep Medicine


This official statement of the American Thoracic Society (ATS) was approved by the ATS Board of Directors, October 2009.
How we measure quality

Structure

Process  Outcome

Donabedian Science 1978
Limited subset of outcome-based quality measures

- Mortality
- Quality of life
- Family satisfaction
- Costs
- Quality of death and dying
We should measure these things when...

- They are important to patients
- They are able to be measured
- The benefits outweigh the risks
We should measure these things when...

- They are important to patients
- They are able to be measured
- The benefits outweigh the risks
Patients value a good death

Factors Considered Important at the End of Life by Patients, Family, Physicians, and Other Care Providers

<table>
<thead>
<tr>
<th>Factor</th>
<th>% of patients rating important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name a decision maker</td>
<td>98%</td>
</tr>
<tr>
<td>Be free of pain</td>
<td>93%</td>
</tr>
<tr>
<td>Be free of shortness of breath</td>
<td>90%</td>
</tr>
<tr>
<td>Presence of family</td>
<td>81%</td>
</tr>
</tbody>
</table>

Steinhauser JAMA 2000
Patients are willing to trade life expectancy for these values

- 75% willing to shorten life to gain quality EOL
- Median time trade-off to alleviate pain and suffering: 7.7 months
We should measure these things when...

- They are important to patients
- They are able to be measured
- The benefits outweigh the risks
Proposed quality measures for palliative care in the critically ill: A consensus from the Robert Wood Johnson Foundation Critical Care Workgroup

Richard A. Mularski, MD, MSHS; J. Randall Curtis, MD, MPH; J. Andrew Billings, MD; Robert Burt, MD; Ira Byock, MD; Cathy Fuhrman, RN, BSN, CCRN, CNRN, CHPN; Anne C. Mosenthal, MD, FACS; Justine Medina, RN, MS; Daniel E. Ray, MD, MS; Gordon D. Rubenfeld, MD, MSc; Lawrence J. Schneiderman, MD; Patsy D. Treece, RN, MN; Robert D. Truog, MD; Mitchell M. Levy, MD, FCCM

<table>
<thead>
<tr>
<th>Domain</th>
<th>Measure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decision making</td>
<td>Assessment of capacity/ ID of surrogate decision maker</td>
</tr>
<tr>
<td></td>
<td>Documentation of advance directives/goals</td>
</tr>
<tr>
<td>Communication</td>
<td>Documentation of timely communication</td>
</tr>
<tr>
<td></td>
<td>Performance and documentation of timely conference</td>
</tr>
<tr>
<td>Continuity</td>
<td>Transition of key information when patient is in ICU</td>
</tr>
<tr>
<td></td>
<td>Policy for nursing continuity</td>
</tr>
<tr>
<td>Support</td>
<td>Open visitation policy</td>
</tr>
<tr>
<td></td>
<td>Documentation of psychosocial/spiritual support</td>
</tr>
<tr>
<td>Symptom management</td>
<td>Pain/respiratory distress assessment and management</td>
</tr>
<tr>
<td></td>
<td>Protocol for withdraw of life support</td>
</tr>
</tbody>
</table>
National quality forum

- US-based clearinghouse for quality measures
- Endorses quality measures upon multiple domains

Importance
Scientific Acceptability
Usability
Feasibility
NQF endorsed measures

<table>
<thead>
<tr>
<th>Domain</th>
<th>Measure</th>
</tr>
</thead>
<tbody>
<tr>
<td>ICU utilization</td>
<td>Percentage of patients who died from cancer admitted to the ICU in the last 30 days of life</td>
</tr>
<tr>
<td>Hospice utilization</td>
<td>Percentage of patients who died from cancer not admitted to hospice</td>
</tr>
<tr>
<td>Preference documentation</td>
<td>Percentage of ICU admissions in which care preferences are documented in first 48 hours</td>
</tr>
<tr>
<td>Pain</td>
<td>Percentage of Pediatric ICU patients receiving pain assessment on admission and periodically thereafter</td>
</tr>
</tbody>
</table>
Other potential domains

• Quality of death and dying
• Good but imperfect psychometric properties

Curtis JPSM 2002
We should measure these things when...

• They are important to patients
• They are able to be measured
• The benefits outweigh the risks
Not measuring EOL quality causes other problems

- Many ICU deaths are “preference sensitive”
- Existing mortality measures incentivize poor quality EOL care
Just across the border

- Mercy Hospital, Buffalo
- “Worst hospitals in America”
- CHF mortality 16.4%
- 40% of deaths previously enrolled in hospice or palliative care

Holloway JAMA 2007
The dying experience varies across like hospitals

- Pennsylvania teaching hospitals
- Same risk-adjusted mortality
- Different end-of-life treatment intensity

Reineck, in preparation
Other risks

• Improving documentation rather than improving quality
• Neglecting unmeasured care
• Minimizing the role of the ICU in palliation
Limitations

• Lack meaningful targets
• Political considerations
# Effect of a Quality-Improvement Intervention on End-of-Life Care in the Intensive Care Unit

**A Randomized Trial**

J. Randall Curtis¹-², Elizabeth L. Nielsen¹, Patsy D. Treece¹, Lois Downey¹, Danae Dotolo¹, Sarah E. Shannon², Anthony L. Back³, Gordon D. Rubenfeld⁴, and Ruth A. Engelberg¹

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Intervention Baseline</th>
<th>Intervention Follow-up</th>
<th>Control Baseline</th>
<th>Control Follow-up</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family QODD</td>
<td>61.8</td>
<td>61.1</td>
<td>59.9</td>
<td>63.7</td>
<td>0.33</td>
</tr>
<tr>
<td>Nurse QODD</td>
<td>69.3</td>
<td>69.7</td>
<td>29.1</td>
<td>68.8</td>
<td>0.81</td>
</tr>
<tr>
<td>Family conference</td>
<td>78.3%</td>
<td>59.8%</td>
<td>76.3%</td>
<td>72.8%</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>No CPR in last hour</td>
<td>87.1%</td>
<td>89.4%</td>
<td>89.4%</td>
<td>87.2%</td>
<td>0.07</td>
</tr>
<tr>
<td>Pain assessment</td>
<td>79.2%</td>
<td>82.2%</td>
<td>77.2%</td>
<td>78.9%</td>
<td>0.81</td>
</tr>
</tbody>
</table>

Curtis AJRCCM 2011
A Communication Strategy and Brochure for Relatives of Patients Dying in the ICU

Alexandre Lautrette, M.D., Michael Darmon, M.D., Bruno Megarbane, M.D., Ph.D., Luc Marie Joly, M.D., Sylvie Chevret, M.D., Ph.D., Christophe Adrie, M.D., Ph.D., Didier Barnoud, M.D., Gérard Bleichner, M.D., Cédric Bruel, M.D., Gérald Choukroun, M.D., J. Randall Curtis, M.D., M.P.H., Fabienne Fieux, M.D., Richard Galliot, M.D., Maité Garrouste-Orgeas, M.D., Hugues Georges, M.D., Dany Goldgran-Toledano, M.D., Mercé Jourdain, M.D., Ph.D., Georges Loubert, M.D., Jean Reignier, M.D., Fayçal Saidi, M.D., Bertrand Souweine, M.D., Ph.D., François Vincent, M.D., Nancy Kentish Barnes, Ph.D., Frédéric Benoit Schlemmer, M.D., and Elie Azoulay, M.D.
Political considerations

Google searches for “death panels” over time

www.google.com/trends
Conclusions

• We should measure quality of care when it’s important to patients and it’s able to be measured
• Alternative is untenable
• Research needed to identify targets
• Don’t let perfect be the enemy of the good
www.ccm.pitt.edu/crisma