The aggressiveness of cancer care near the end of life: Is it a quality of care issue?

Craig C. Earle, MD
Overview

1. Identifying and validating potential measures of the quality of end of life cancer care from administrative data
2. Trends in the aggressiveness of cancer care near the end of life
3. Measure application
4. Ongoing development
5. Discussion
Level of concentration vs. time from start of lecture

Q: Why measure the quality of health care?
A: To improve the quality of health care.

- Physicians respond to:
  - Financial incentives (performance bonuses)
  - Administrative sanctions
  - Monitoring and feedback

  “create an environment of watchful concern that motivates everyone to perform better”
  - Donabedian
Poor quality care

is when “practices of known effectiveness are being **underutilized**, practices of known ineffectiveness are being **overutilized**, and services of equivocal effectiveness are being utilized in accordance with provider rather than patient preferences (**misuse**)”

– National Cancer Policy Board (bolding mine)
The importance of quality in advanced cancer/end-of-life care

- Cancer quality indicators to date focus on screening and initial management
- Breast cancer dominates the quality literature
- However, over half of cancer patients either present with or eventually develop terminal metastatic disease
- Many of the management issues for advanced cancer are the same, regardless of original tumor type

=> Therefore, the quality of end-of-life cancer care affects a lot of patients
A review of the quality literature described “a dramatic lack of data addressing” quality issues for incurable malignancies.
Methods of monitoring care

• Medical record chart reviews
  – Expert judgment
• Patient assessment and survey
• Administrative (billing) records and cancer registries
Advantages of using administrative data to monitor quality

- Already exists
- Objective
- Easily captured in real time (computer readable)
  - Can give prompt feedback to providers
- Inexpensive
- Large sample sizes
- Less selection bias
Disadvantages of administrative data

• Clinical information is lacking or must be inferred (comorbidities etc.)
• No information on patient preferences
• Technical or interpersonal skills not reflected
• Problems with accuracy and completeness
  – data not created for research or quality monitoring
Identifying potential indicators of the quality of end of life cancer care from administrative data - J Clin Oncol 2003;21(6):1133-8

**Objective:**

- To identify feasible indicators that could use existing administrative data to evaluate the quality of end-of-life cancer care for patients with incurable malignancies.
Qualitative Methods

• Literature Review

• Focus groups
  – Patients
  – Families

• Expert Panel of health care providers
  – Modified Delphi approach to approve and rank indicators
“You’ve got six months, but with aggressive treatment we can help make that seem much longer.”
Major Themes

• *Overuse* of chemotherapy near death
• *Underuse* of hospice services
• “*Misuse*” of interventions, causing high rates of complications that result in Emergency Room visits, hospitalization, or intensive care admissions
Institution of new anti-cancer therapies or continuation of ongoing treatments very near death may indicate overuse

- The concept ranked highest by the expert panel
  “We can treat with many lines of chemotherapy in appropriate patients, but there’s a time to stop.” (medical oncologist)
- Family members supported this more strongly than patients
A high number of emergency room visits, inpatient hospital admissions, and days spent in the ICU near the end of life may indicate poor quality care

• “I’ve come to terms with dying from my cancer. I don’t want to die from complications of the treatment.” (patient)
• “For most of our patients, a visit to the ICU is kind of a failure.” (medical oncologist)
A high proportion of patients never referred to hospice or only referred in the last few days of life, or death in an acute care setting, may indicate poor quality care

• “I think the earlier the doctor mentions (hospice), the better it is for the patient because the patient could plan for things ahead, rather than to spend so much time doing the treatment.” (family member)

• Expert panel felt hospice use may reflect resources available in a local healthcare system rather than patient or physician decisions.

• Ranked very highly the concept that high rates of death in hospital or ICU may indicate poor quality care.
Important issues not currently amenable to administrative data

- Psychosocial care
- Multidisciplinary treatment
- Pain and symptom management
- Advance directives
- Shared decision-making
- Communication
Methodologic Evaluation


- Indicators operationalized and performance evaluated
  - Accuracy
  - Variation
  - Reliability
  - Achievable benchmarks
  - Beginning of validity testing
In the course of these exercises, secular trends became apparent.
Trends in the Aggressiveness of cancer care near the end of life

- J Clin Oncol 2004;22(2):315-21

Objectives

- To characterize the aggressiveness of end-of-life cancer treatment,
- its relation to the availability of health care resources, and
- observe trends over time.
Methods: Data sources

**SEER** (Surveillance, Epidemiology, and End Results)

- National Cancer Institute (NCI)
- 11 tumor registries
- ~ 14% of the US population
- Demographically fairly representative
SEER data elements

• Disease specifics
  – cancer site, stage, histology, date of diagnosis, date and cause of death

• Socio-demographics
  – age, sex, race/ethnicity, census-tract level wealth and education

• Treatment:
  – surgery and radiation within the first 4 months
SEER alone does not provide complete treatment data:

- Chemotherapy not reliably captured; not released
- No information on treatments beyond 4 months from diagnosis
- No information on other interventions (hospitalizations, hospice use etc.)
Medicare

• Center for Medicare and Medicaid Services (CMS)
• Patients over age 65, disability, ESRD
• Retains billing files for: inpatient, outpatient, physician and lab billing, home health, hospice
SEER-Medicare

• Medicare files for patients over age 65 linked to SEER with a 94% match rate
• SEER cases diagnosed through 1996
• Medicare claims through 1998

SEER+Medicare = diagnostic and treatment data
Explanatory variables

• Co-morbid conditions identified through diagnostic codes in the year prior to diagnosis using Charlson/Deyo/Klabunde

• Care in a Teaching Hospital defined as any inpatient bill for indirect medical education.

• SES deciles based on race/age-adjusted income and wealth
Unit of analysis: Health Care Service Area (HCSA)

- Groupings of Metropolitan Statistical Areas (MSA) defined by observed patient flow in Medicare (referral patterns etc.)
- Considered to be self-contained regional health systems
Local availability of resources

- **Area Resource File (National Center for Health Workforce Information and Analysis)**
  - per capita density of physicians, medical specialists, and radiation oncologists derived from the AMA Master File;
  - density of hospitals, teaching hospitals, hospital beds, hospitals with oncology services, and hospices were taken from the County Hospital File.
Cohort Selection

• All patients living in a SEER area at diagnosis who died of lung, breast, colorectal, and other gastrointestinal cancers between 1991-1996
  – 60% of cancer deaths, use chemotherapy
• Complete bills: dx - death
  – Eligible for both parts of Medicare
  – Never enrolled in an HMO
• Eligible for Medicare on the basis of age
• Survived < 1 year (aggressive cancers)
Chemotherapy use

- The proportion receiving chemotherapy rose from 27.9% in 1993 to 29.5% in 1996.

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<tr>
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</thead>
<tbody>
<tr>
<td>last chemo dose*</td>
<td>71.0</td>
<td>69.0</td>
<td>67.4</td>
<td>65.3</td>
</tr>
<tr>
<td>start of last chemo regimen*</td>
<td>140.5</td>
<td>133.4</td>
<td>130.4</td>
<td>127.7</td>
</tr>
</tbody>
</table>

- The mean duration of the last course was stable at 61 d

*p < .05
“You’ve come to the right place, Ms. Colburne. I specialize in futile treatment”
Complications in the last month of life

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</thead>
<tbody>
<tr>
<td># ER visits*</td>
<td>.40</td>
<td>.43</td>
<td>.46</td>
<td>.46</td>
</tr>
<tr>
<td>Inpatient days</td>
<td>4.8</td>
<td>4.6</td>
<td>4.5</td>
<td>4.7</td>
</tr>
<tr>
<td>ICU admissions*</td>
<td>.10</td>
<td>.10</td>
<td>.11</td>
<td>.12</td>
</tr>
<tr>
<td>ICU days*</td>
<td>.52</td>
<td>.53</td>
<td>.53</td>
<td>.61</td>
</tr>
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*p<.05, all more common among patients receiving chemotherapy
## Hospice Utilization

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</thead>
<tbody>
<tr>
<td>% admitted to hospice*</td>
<td>28.3</td>
<td>34.4</td>
<td>35.5</td>
<td>38.8</td>
</tr>
<tr>
<td>% dying in an acute care institution*</td>
<td>32.9</td>
<td>30.6</td>
<td>29.7</td>
<td>29.5</td>
</tr>
<tr>
<td>Avg days in hospice*</td>
<td>34.1</td>
<td>34.1</td>
<td>34.7</td>
<td>32.7</td>
</tr>
</tbody>
</table>

*p<.05

Being discharged from hospital to die in hospice?
Indicators
(looking for rates of outliers)

- Last dose of chemo within 14d of death
- ICU admission in the last month of life
- > 1 ER visit in the last month of life
- Last chemo regimen started within 30 d of death

% of patients
Relationship between the aggressiveness of cancer care and hospice utilization

- Number of indicators of aggressive care
- Percent admitted to hospice
## Associations with Aggressive Care

<table>
<thead>
<tr>
<th></th>
<th>OR</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Year of death</td>
<td>1.06</td>
<td>(1.02, 1.10)</td>
</tr>
<tr>
<td>Age</td>
<td>0.98</td>
<td>(0.97, 0.99)</td>
</tr>
<tr>
<td>Female</td>
<td>0.80</td>
<td>(0.73, 0.87)</td>
</tr>
<tr>
<td>Comorbidity</td>
<td>1.14</td>
<td>(1.06, 1.23)</td>
</tr>
<tr>
<td>Teaching hospital</td>
<td>1.24</td>
<td>(1.12, 1.38)</td>
</tr>
<tr>
<td>Black race</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Teaching hospitals</td>
<td>0.80</td>
<td>(NS)</td>
</tr>
<tr>
<td>Non-teaching hospitals</td>
<td>1.25</td>
<td>(1.01, 1.55)</td>
</tr>
<tr>
<td>Density of teaching hospitals</td>
<td>1.10</td>
<td>(1.04, 1.17)</td>
</tr>
<tr>
<td>Density of hospices</td>
<td>0.93</td>
<td>(0.88, 0.98)</td>
</tr>
</tbody>
</table>
Updated data: all cancers, all survival lengths

% of patients

> 1 ER visit in the last month of life
< 3 days in hospice\(^1\)
Last dose of chemotherapy within 14 days of death
ICU admission in the last month of life
> 1 hospitalization in the last month of life
Last chemotherapy regimen started within 30 days of death

\(^1\)Among patients admitted to hospice
QOPI : Quality Oncology Practice Initiative

- 125 practices, > 2000 MDs, 10,000 patients
- Chemotherapy use within 14 days of death ranged from 0 to 53% in participating practices
- Strongly correlated to admission to hospice < 1 week before death (p=.03)
  
  (Proc Am Soc Clin Oncol Abstr. 8573)
...why do they put nails in coffins?
Quality Oncology Practice Initiative (QOPI)

Patient enrolled in hospice before death

Mean=62%
Being considered for application by:

- National Quality Forum (NQF)
  - Surveillance measures for end-of-life care
- National Quality Measures Clearinghouse (NQMC - AHRQ)
- Partners Healthcare

Attractiveness:
- End-of-life
- Methodological development
- Feasible
- Address overuse
Validity testing: Do these issues affect family satisfaction with care?

Patient and Caregiver Study (E. Grunfeld, PI)

• Small (51 patient) validation study related these measures to family member’s satisfaction with care (FAMCARE instrument) as death approached for 51 women that died of breast cancer.

• Trends: worse satisfaction associated with:
  – Chemotherapy overuse
  – Death in hospital or ICU
  – No hospice admission or shorter LOS in hospice

• ‘Information giving’ and ‘physical care’ subscales drove the results.
Does aggressive treatment improve survival?

Stage IV NSCLC SEER-Medicare patients who survive at least 3 months after diagnosis:

- Unadjusted and adjusted (Cox PH) survival
- Propensity Score stratification
- Instrumental variable analysis
  - Geographic variation in practice as the instrument
Stage IV NSCLC survival
A research program to understand treatment choices and outcomes of colorectal cancer and lung cancer
Patients from population-based cohorts in geographic areas

Patients from integrated health care delivery systems

Patients at Veterans Health Administration hospitals

CanCORS Sites

Group Health Cooperative
(Seattle metropolitan area)

Kaiser Permanente Northwest
(Portland metropolitan area)

Group Health Cooperative
(Seattle metropolitan area)

Kaiser Permanente Northwest
(Portland metropolitan area)

Northern California
(8 counties in San Jose, San Francisco/Oakland, and Sacramento areas)

Kaiser Permanente Hawaii
(4 major islands)

Los Angeles County

State of Iowa

Chicago, IL
(Lakeside and Hines)

Indianapolis, IN

Henry Ford Health System
(Detroit metropolitan area)

Harvard Pilgrim Health Care
(Boston metropolitan area)

New York, NY

Baltimore, MD

Durham, NC

North Carolina
22 central/eastern counties

Nashville, TN

Atlanta, GA

Henry Ford Health System
(Detroit metropolitan area)

Minneapolis, MN

Chicago, IL
(Lakeside and Hines)

Indianapolis, IN

Biloxi, MS

State of Alabama

Houston, TX
Planned validation study

- 5,000 patients with lung, 5,000 with colorectal CA
- Estimate 3,000 lung cancer deaths, 1,000 colorectal cancer deaths in 15 months
- Based on SEER data ~ 65% will be > 65 yo
- ~ 85% in FFS Medicare

⇒ 1,675 lung and 578 colorectal cancer patients
⇒ Purchase their Medicare claims
‘Proxy after Death’ survey
Overall, how would you rate the care that [NAME OF PATIENT] received in [HIS/HER] last month of life?

<p>| | |</p>
<table>
<thead>
<tr>
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<tbody>
<tr>
<td>EXCELLENT</td>
<td>1</td>
</tr>
<tr>
<td>VERY GOOD</td>
<td>2</td>
</tr>
<tr>
<td>GOOD</td>
<td>3</td>
</tr>
<tr>
<td>FAIR</td>
<td>4</td>
</tr>
<tr>
<td>POOR</td>
<td>5</td>
</tr>
</tbody>
</table>
Analysis

• Relate the measures of potentially overly aggressive care to perceptions of quality

• Also secondary analyses relating them to perceptions of whether the patient received the right amount of help for pain and anxiety/depression

• Describe patient, provider, and health system characteristics associated with aggressive care
  – including provider’s ‘propensity to treat’
Other ongoing work

- Different patient populations (younger, different cancers, different countries)
- Relationship to social determinants
- Effect of managed care penetration
- AHRQ DEcIDE task order
  - Prospectively identify terminal phase?
Rationales for futile chemotherapy

Evidence shows aggressiveness of chemotherapy near death is unrelated to the likelihood of success of treatment, however:

• Patients often request it
• Seen as preserving ‘hope’, being a ‘fighter’ or ‘winner’
• ‘doing something is better than doing nothing’
• It’s easier (for us)
• The occasional patient does respond and have meaningful palliation
• Patients will accept much more toxicity for less benefit than health care providers would
• Financial incentives? (Health Affairs 2006;25(2):437-43)
Hospice

- HMO patients are more likely to be referred to hospice and to be referred in a timely manner
  - Are oncologists pressured by HMOs to switch patients from active chemotherapy to hospice care?
- Currently reimbursed $100-120/day

=> Impact on expensive palliative interventions
  - RT, growth factors, narcotic pumps, biological agents
“My friends, we can and we will never, never surrender to what is right”

- J Danforth Quayle
Is this a quality of care issue?

- The utility of any of these measures depends on whether the concept of overuse near death is acceptable to the various stakeholders as a valid quality issue.
- How easy is it to identify the end-of-life period prospectively?
- Is it possible to both achieve patient satisfaction and avoid futile care?
“The quality of medical care would be far better and the hazards far less if physicians, like pilots, were passengers in their own airplanes... We are.”

- D. Berwick
Discussion
Methods: Accuracy

- Local tumor registry at DFCI & BWH
- 150 consecutive patients who died of lung, breast, colorectal, and other gastrointestinal cancers
- Obtained billing claims and validated measures against detailed medical record review
- Expressed as proportion with dates in claims within +/- 1 day of date from medical record review
<table>
<thead>
<tr>
<th>Measure</th>
<th>Sens</th>
<th>Spec</th>
<th>Acc</th>
</tr>
</thead>
<tbody>
<tr>
<td>Last chemotherapy dose</td>
<td>.92</td>
<td>.94</td>
<td>.92</td>
</tr>
<tr>
<td>Last new chemotherapy regimen</td>
<td>.83</td>
<td>.94</td>
<td>.85</td>
</tr>
<tr>
<td>ER visit</td>
<td>.82</td>
<td>.96</td>
<td>.89</td>
</tr>
<tr>
<td>Hospitalization</td>
<td>.96</td>
<td>1.0</td>
<td>.97</td>
</tr>
<tr>
<td>ICU admission</td>
<td>.87</td>
<td>.97</td>
<td>.89</td>
</tr>
<tr>
<td>Hospital length of stay</td>
<td>.95</td>
<td>1.0</td>
<td>.96</td>
</tr>
<tr>
<td>Death in an acute care hospital</td>
<td>.85</td>
<td>1.0</td>
<td>.97</td>
</tr>
<tr>
<td>Hospice LOS</td>
<td>.24</td>
<td>.97</td>
<td>.81</td>
</tr>
</tbody>
</table>
Geographic Variation

• Hierarchical regression modeling
• Adjust for patient disease and sociodemographic characteristics

• Looked for significant variation in:
  rate of the indicator in a HCSA at the 5th percentile
  rate of the indicator in a HCSA at the 95th percentile
Results: Variability (SEER-Medicare)

<table>
<thead>
<tr>
<th>Measure</th>
<th>Variability</th>
</tr>
</thead>
<tbody>
<tr>
<td>% receiving chemo, last 14 d. of life</td>
<td>2.24 (1.74-2.97)</td>
</tr>
<tr>
<td>% starting new chemo, last 30 d. of life</td>
<td>3.19 (2.03-5.41)</td>
</tr>
<tr>
<td>&gt;1 ER visit, last 30 d. of life</td>
<td>2.78 (2.04-3.88)</td>
</tr>
<tr>
<td>&gt;1 hospitalization, last 30 d. of life</td>
<td>2.38 (1.85-3.16)</td>
</tr>
<tr>
<td>ICU admissions, last 30 d. of life</td>
<td>3.28 (2.38-4.67)</td>
</tr>
<tr>
<td>Death in an acute care hospital</td>
<td>2.49 (2.05-3.12)</td>
</tr>
<tr>
<td>Lack of admission to hospice</td>
<td>5.00 (3.76-6.89)</td>
</tr>
<tr>
<td>Hospice admission &lt; 3 days before death</td>
<td>2.39 (1.99-2.95)</td>
</tr>
</tbody>
</table>
Reliable measures

![Graph showing Reliable measures over years with East, West, and North lines on a Y-axis ranging from 0 to 80 and an X-axis from 1991 to 1999. The East line is in diamonds, the West line in yellow squares, and the North line in green triangles.](image-url)
Unreliable measures
Correlation in HCSA ranks over time

Prior to death:

<table>
<thead>
<tr>
<th>Correlation in Ranks</th>
<th>Chemo in last 2 weeks</th>
<th>ICU in last 30d</th>
<th>Hospice LOS &lt;3d</th>
</tr>
</thead>
<tbody>
<tr>
<td>1991-1995</td>
<td>.73</td>
<td>.84</td>
<td>.79</td>
</tr>
<tr>
<td>1991-2000</td>
<td>.54</td>
<td>.61</td>
<td>.44</td>
</tr>
</tbody>
</table>

HCSA=Health Care Service Area; LOS=Length of Stay
Empirical determination of achievable benchmarks

Pared-mean method:

• HCSAs ranked in order of the proportion experiencing the measure

• Beginning with the best-performing HCSA, HCSAs sequentially added until the selected subset cares for 10% of the population

Benchmark = \[
\frac{\text{# patients experiencing the indicator}}{\text{Total # patients in the 10% subset}}
\]
## Results: Achievable Benchmarks (SEER-Medicare)

<table>
<thead>
<tr>
<th>Measure</th>
<th>Benchmark</th>
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</thead>
<tbody>
<tr>
<td>% receiving chemo, last 14 d. of life</td>
<td>&lt; .10</td>
</tr>
<tr>
<td>% starting new chemo, last 30 d. of life</td>
<td>&lt; .02</td>
</tr>
<tr>
<td>% &gt;1 ER visit, last 30 d. of life</td>
<td>&lt; .04</td>
</tr>
<tr>
<td>% &gt;1 hospitalization, last 30 d. of life</td>
<td>&lt; .04</td>
</tr>
<tr>
<td>ICU admission, last 30 d. of life</td>
<td>&lt; .04</td>
</tr>
<tr>
<td>&gt;14 d. in hospital, last 30 d. of life</td>
<td>&lt; .04</td>
</tr>
<tr>
<td>Death in an acute care hospital</td>
<td>&lt; .17</td>
</tr>
<tr>
<td>Lack of admission to hospice</td>
<td>&lt; .45</td>
</tr>
<tr>
<td>Admission to hospice &lt; 3 days before death</td>
<td>&lt; .08</td>
</tr>
</tbody>
</table>
• Why measure the quality of care?

• Why end-of-life care?

• Why administrative data?