Death as Great Equalizer?
Recognizing & Reducing Disparities in End-Stage Cancer Care

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Hamlet Act IV, Scene 3

Hamlet: “A man may fish with the worm that hath eat of a king, and eat of the fish that hath fed of that worm...

Claudius: “What dost you mean by this?”

Hamlet: “Nothing but to show you how a king may go a progress through the guts of a beggar.”

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- Hamlet’s quote exemplifies the proverb of death being the great equalizer
- The king and beggar, while distinctly different in life, are both simply food for worms in death
YET...

- while we may all be the same in death,
- we do **not** all die the same

### End-of-Life (EoL) Care

**Worse** = *more* burdensome, unbenefficial/futile, aggressive EoL care; *less* value-consistent care

**Better** = *less* burdensome, unbenefficial/futile, aggressive EoL care; *more* value-consistent care

<table>
<thead>
<tr>
<th>Better EoL Care</th>
<th>Worse EoL Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Whites</td>
<td>- Blacks</td>
</tr>
<tr>
<td></td>
<td>- Latinos</td>
</tr>
<tr>
<td>- US-born</td>
<td>- Immigrant</td>
</tr>
<tr>
<td>- Older</td>
<td>- Younger</td>
</tr>
<tr>
<td>- Women</td>
<td>- Men</td>
</tr>
<tr>
<td>- Non-religious copers</td>
<td>- Religious copers</td>
</tr>
<tr>
<td>- Depressed</td>
<td>- Anxious</td>
</tr>
</tbody>
</table>
Why is more aggressive EoL care worse care?
Because...

**Increased** number of procedures - resuscitation, ventilation, feeding tubes, Intensive Care Unit stays

**Decreased** quality of life, as rated by family

More aggressive care is associated with worsened quality of life

Wright et al. JAMA 2008
End-of-life care is EXPENSIVE.

Disproportionate amount of money spent on end-of-life care:

- 25% of Medicare costs spent on 5% of patients in their last year of life
- 40% of that is for care in last month of life
Can’t Buy a Better Death: The High Cost of Burdensome Care

Increased cost of late-term interventions

Lower quality of death

Zhang et al. Arch Int Med 2009
Findings from Coping with Cancer NCI R01s re: disparities in end-of-life care

- **Race**: black patients receive more aggressive end-of-life care and less value-consistent care

- **Gender**: male patients receive more aggressive end-of-life care

- **Immigrant vs. US-born**: immigrant patients receive more aggressive end-of-life care and less value-consistent care

- **Religious Copers vs. non-Religious Copers**: religious copers receive more aggressive end-of-life care

- **Patients who are psychologically numb or in shock**: Numb/anxious patients receive more aggressive end-of-life care
WHAT DO ALL THESE PATIENT GROUPS HAVE IN COMMON?

Each of these risk factors is associated with patient’s lack of prognostic understanding; that is, the “gist” that they are dying (e.g., have months, not years, left to live)

- **Race/Ethnicity**: black and Latino advanced cancer patients are less likely to get the gist that they’re dying

- **Gender**: male patients are less likely to get the gist that they are dying

- **Immigrant vs. US-born**: immigrant patients are less likely to get the gist that they’re dying

- **Religious Copers vs. non-Religious Copers**: religious copers less likely to get the gist that they’re dying

- **Patients who are psychologically numb or in shock**: numb/anxious patients are less likely to get the gist that they’re dying
How to we promote patient’s get the gist that they have months, not years left to live?
Getting Information Simply and Transparently (GIST): A Big Picture Approach to Improved EoL Decision-Making

Influences on Gist

- Socio-demographic
  - Age
  - Gender
  - Education
  - Race
  - Ethnicity
- Psychological
  - Anxiety
  - Depression
  - Pain
  - Stress
  - Other psychological factors
- Cultural
  - Ethnic identity
  - Religious beliefs
  - Other cultural factors
- Physiological
  - Symptoms
  - Performance status
  - Other physiological factors
- Clinical
  - Communication
  - Inpatient & outpatient
  - Prioritization

The GIST

Patient gets the gist (e.g., realizes s/he likely has months, not years, left to live)

End-of-Life (EoL) Decision-Making

- Treatment Preferences
- Goals of Care
- Advanced Care Planning
  - DNR
  - Advanced Directive

Gist Outcomes

- Medical Decision-Making
- EoL Decision-Making
- End-of-Life Outcomes
  - Patient Care
  - Value-consistent
  - Life-prolonging
  - Palliative
  - Hospice
  - Chaplain Visits
  - Other supportive services
  - Quality of Life
  - Quality of Death
  -Severity of Suffering
  - Caregiver
  - Bereavement adjustment
  - PND
  - PTSD

Clearly, there's a need for better clinical communication.
Prognosis (months, not years) should be discussed by Oncolo-GIST
Oncologists need to discuss prognosis

Patients who discussed their re-staging scans with oncologist vs. fellow or NP better recognize late- or end-stage of their disease

<table>
<thead>
<tr>
<th>Odds Ratio</th>
<th>Unadjusted</th>
<th>Adjusted</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2.44</td>
<td>3.08</td>
</tr>
<tr>
<td>Confidence interval</td>
<td>(1.10, 5.43)</td>
<td>(1.02, 9.33)</td>
</tr>
<tr>
<td>P-value</td>
<td>0.028</td>
<td>0.046</td>
</tr>
</tbody>
</table>

Control variables
- Pre-scan illness understanding
- Clinic
- Physical symptom distress

Cohen et al. 2018
Rate of agreement between oncologist and patient for male & female oncologists

*Adjusted for patient gender

![Bar chart showing curability and prognosis for males and females.]

Curability:
- Males: 77%
- Females: 39%

Prognosis:
- Males: 35%
- Females: 74%

Rate of agreement between oncologist and patient for male & female oncologists is adjusted for patient gender.

Epstein et al. in prep.
Numbness modifies effect of EoL discussion on EoL care
Figure 2. EMPOWERing Patients to Cope by Reducing Experiential Avoidance

**EMPOWER**
- Acknowledge potentially stressful situation
- Engage in mindfulness, breathing, & grounding exercises
- Provide psychoeducation re: peritraumatic stress, anticipatory grief, & experiential avoidance
- Review cognitive-behavioral and acceptance-based strategies to build distress tolerance
- Invoke patient’s values and perspective to aid in surrogate decision-making

**EMPOWER = Enhancing & Mobilizing the POTential for Wellness & Emotional Resilience**
Thank you!

Holly Prigerson: hgp2001@med.cornell.edu
Where Do Black Patients Get Their Information About Their Prognosis? (CwCI)

Source Estimate of Life Expectancy (White Race)
- Oncologist, clinic staff, and palliative care physician: 4%, 2%
- Patient belief: 10%, 5%
- Religious belief: 42%, 21%
- Other: 142, 72%

Source Estimate of Life Expectancy (Black Race)
- Oncologist, clinic staff, and palliative care physician: 0, 0%
- Patient belief: 11, 35%
- Religious belief: 20, 65%
- Other: 0, 0%

Figure 4. ICU admissions/deaths in the last week of life by spiritual care from the health care team

Balboni et al. AAHPM 2011
<table>
<thead>
<tr>
<th></th>
<th>Male</th>
<th>Female</th>
<th>AOR*</th>
<th>N</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Post-Scan</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• TIA</td>
<td>58.1</td>
<td>57.8</td>
<td>0.80</td>
<td>76</td>
<td>0.70</td>
</tr>
<tr>
<td>• Curable</td>
<td>36.7</td>
<td>10.9</td>
<td>4.56</td>
<td>76</td>
<td>0.03</td>
</tr>
<tr>
<td>• Late stage</td>
<td>38.7</td>
<td>63.0</td>
<td>0.25</td>
<td>77</td>
<td>0.02</td>
</tr>
</tbody>
</table>

Adjusted for race and site
### Gender differences in illness understanding

<table>
<thead>
<tr>
<th></th>
<th>OR adj for “pre”</th>
<th>OR adj for <em>prognostic discussion</em></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>AOR</td>
<td>P</td>
</tr>
<tr>
<td><em>Post-scan</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TIA</td>
<td>0.93</td>
<td>0.93</td>
</tr>
<tr>
<td>Curable</td>
<td>9.49</td>
<td>0.03</td>
</tr>
<tr>
<td>Late-stage</td>
<td>0.05</td>
<td>0.03</td>
</tr>
</tbody>
</table>

Gender differences in illness understanding

Genders differences in illness understanding

Fletcher et al. JSO 2013
Figure 1  Relative Odds\(^1\) of Receipt of ICU Care at the End of Life (EoL) by Gender and EoL Discussion (N=353)

\[\text{Relative Odds, ICU @ EoL}\]

\[\begin{align*}
\text{Men, No EoL Discussion} & : 4.0 \\
\text{Women, No EoL Discussion} & : 2.0 \\
\text{Men, EoL Discussion (Ref)} & : 1.0 \\
\text{Women, EoL Discussion} & : * p < 0.05
\end{align*}\]

\(^1\) Relative odds for ICU @ EoL, adjusted for baseline DNR order completion and for baseline preference for palliative EoL care, using men reporting EoL discussions at baseline as a reference group.
EOL Care: White ≠ Black

• Aggressive EOL care = advanced cancer patients’ ventilation &/or resuscitation in the last week of life, + die in ICU
  – Black > white patients received aggressive EOL care
    ➢ 13.2% black vs. 3.4% white
    ➢ AOR = 3.04; p=0.037

Trice-Loggers et al. *JCO* 2009
Race/ethnicity moderates effect of EOL discussions on “communication goals”...

- Effects of EOL discussions on terminal illness acknowledgment (TIA) differ by patient’s race (Wald $\chi^2 = 50.77$, df=1, p=0.0001)
**Relationship between EOL Discussions & EOL Care**

<table>
<thead>
<tr>
<th>EOL Care in last week</th>
<th>Black Patients</th>
<th>White Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Adj. OR</td>
<td>P-value</td>
</tr>
<tr>
<td>• Aggressive EOL care</td>
<td>0.29</td>
<td>.12</td>
</tr>
<tr>
<td>• EOL care = patient wishes</td>
<td>1.61</td>
<td>.45</td>
</tr>
</tbody>
</table>