Meet Ms. Hoover

You are discussing treatment preferences with an elderly woman with CHF, DM and COPD who was admitted after a fall at home. She expresses frustration with her progressive weakness, pain and sadness at her growing dependence on others. The patient has no prior advance directives. When asked whether she would want to be resuscitated if her heart stopped, she states “Why not? It seems I don’t have much to lose at that point, do I, doctor?”

Best evidence suggests that the patients and families overestimate the chances of survival (to hospital discharge) following in-hospital resuscitation by:

1. 50%
2. 100%
3. 200%
4. 500%
True or false? Best evidence shows that patients who complete advance directives are less likely to die in the hospital.

1. True
2. False

Studies from Oregon suggest that, compared to other patients receiving hospice care, patients who request and receive prescriptions for lethal medications are much more likely to:

1. Fear the process of dying
2. Fear losing control of circumstances of death
3. Suffer from depression
4. Suffer from pain
5. Fear burdening others

Today’s Spotlight
1. Describe how Hollywood’s depiction of death and dying fuels societal fear and influences end-of-life policy
2. Explain how film makers’ illustration of end-of-life care often propagates ethical myths or misconceptions that sometimes undermine the process of informed consent.
3. Using examples of the diverse emotions portrayed in end-of-life film, defend the phrase: “Dying is fundamentally a personal experience, not a set of medical problems to be solved.” (Dr. Ira Byock).
“For many, the most common images of death are those presented in the news and entertainment media, which tend to focus on the sensational, violent or sentimental and which often depict death as an event without much social or personal context.”

From "A Profile of Death and Dying in America", National Academies Press, 1997

Films Exploring Death and Dying

The Big Chill
The Sea Inside
Barbarian Invasions
Terms of Endearment
Tuesdays With Morrie
Life as a House
Big Fish
On Our Own Terms
Dead Man Walking
Brian’s Song
Million Dollar Baby
Cries and Whispers
Dead Poet’s Society
Dying Young
In America
The Fire Within

The Doctor
The Hours
Stand By Me
Ikaru
Philadelphia
Lorenzo’s Oil
One True Thing
All That Jazz
Rockaby
Shadowland
Steel Magnolias
Wit
Platoon
Up
Beaches
Many more!
A Production in Two Acts

1. Death: the Enemy
   • A Culture of Fear
   • Defiance and Denial

2. Death: a Part of Life
   • Planning Ahead
   • A “Personal Experience”

A Culture of Fear

• Death in America: the last taboo, diversity
• Common fears:
  – Fear of the dying process, pain, control, burden
  – Existential concerns (Why? Will I be remembered?)
• Responses to fear:
  – Avoidance and denial
  – Defiance: death, the enemy
  – Taking control
  – Adaptation and acceptance

Denial: Only Cure

The Fountain, 2006
Concerns About an “Undue” Exit…

“Duty to Die”

Scripted “Early” Endings...

Soylent Green, 1973
Logan’s Run, 1976

Modern Media: Squelching Dialogue, Influencing Policy
Obliged to Offer Something?

“More than 40% of oncologists report offering treatments that they believe are unlikely to work.”

— Atul Gawande, New Yorker, 2010

The Other End of the Spectrum: The “Right to Die” Movement

Three Pivotal Conversations…

1. Quinlan (1976): young woman in PVS; parent’s request to remove ventilator initially blocked (until court intervenes)
2. Cruzan (1990): young woman in PVS; parent’s request to remove feeding tube initially blocked (later reversed)
3. Schiavo (2005): young woman in PVS; husband’s request to remove feeding tube initially blocked (later reversed)
### Seeking End-of-Life Control

**Increasing Ethical/Legal Controversy**

- Refusal of Life-Sustaining Therapies
- Palliative Care Services
- Voluntary Refusal of Food and Fluids
- Physician Assisted Death
- Euthanasia
- Palliative Sedation Therapy
- Suicide

### Seeking…and Getting Help

Million Dollar Baby, 2004

### A Question to Ponder…

**Case 1:** A ventilator-dependent quadriplegic requests ventilator withdrawal

**Case 2:** Quadriplegic, who has regained spontaneous breathing and weaning from the ventilator, requests a lethal dose of medication

Is the doctor morally responsible for each of these deaths?
Challenging the Status Quo…

Assisted Death: Oregon Experience

Physician Assisted Death (PAD)
- 1 in 6: talk w/ family
- 1 in 50: talk w/ their MD
- 1 in 100: request PAD
- 1 in 1000: PAD deaths

Findings From Oregon…

Why do people seek physician-assisted death?

<table>
<thead>
<tr>
<th>Category</th>
<th>% “Much more” or “more” than other hospice patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fear of loss of control over death</td>
<td>77%</td>
</tr>
<tr>
<td>Fear of mental decline</td>
<td>49%</td>
</tr>
<tr>
<td>Fear of burdening others</td>
<td>36%</td>
</tr>
<tr>
<td>Depression</td>
<td>23%</td>
</tr>
<tr>
<td>Fear of process of dying</td>
<td>17%</td>
</tr>
<tr>
<td>Pain</td>
<td>15%</td>
</tr>
</tbody>
</table>

Ganzini et al. NEJM, 2002

Control through Voluntarily Stopping Eating and Drinking (VSED)

- Survey of 307 Oregon hospice RNs re: VSED
- VSED common
- Reasons for VSED:
  - Ready to die, further life pointless, poor QOL, wanting control
- RNs rated deaths more peaceful/less suffering

Ganzini et al., NEJM, 2003

Cultivating Dialogue…

“Approaching the problem of suffering among the dying through the lens of assisted-suicide is like looking through the wrong end of binoculars; it narrows and distorts the view. Success will not come with making assisted suicide and euthanasia legal, but rather with making them unnecessary…”

Ira Byock, MD

Palliative Care: Adding Quality AND Quantity

- Randomized trial of 151 patients w/ lung CA
- Patients randomized to usual care vs. usual care PLUS early (integrated) palliative care
- Those with early palliative care had:
  - Higher quality of life scores (p=0.03)
  - Fewer depressive symptoms (16% vs. 38%, P=0.01)
  - Less “aggressive” EDL care (33% vs. 54%, P = 0.05)
  - Longer survival (11.6 months vs. 8.9 months, P = 0.02)

Temel JS et al., NEJM, 2010
A Production in Two Acts

1. Death: the Enemy
   • A Culture of Fear
   • Defiance and Denial
2. Death: a Part of Life
   • Planning Ahead
   • A “Personal Experience”

End-of-Life Discussions Alter Care

- Studies show EOL discussions associated with:
  - NO increase in patient depression or worry
  - Better patient and caregiver quality of life
  - ↓ Ventilation, resuscitation, ICU admission; ↓ costs
  - Earlier hospice admissions
  - Less depression in bereaved caregivers
- More aggressive therapies associated with:
  - NO difference in mortality
  - Worse patient quality of life (↑ Hospice LOS =↑ QOL)


Directives Influence Care

- Survey of 3746 proxies of decedent patients
- Nearly half (43%) required decision making:
  - 70% lacked capacity, 68% (of those) had ADs
- Those with ADs (either living will or MDPOA):
  - More likely to want limited care (93%) or comfort care (96.2%) vs. “all care possible” (1.9%)
  - Less likely to die in hospital (AOR=0.72) or receive “all care possible” (AOR=0.54)

Silveira MJ et al. NEJM, 2010
Medical Care by TV:
A “Typical” TV Resuscitation…

“CPR on TV — Miracles and Misinformation”
- Public perception shaped by TV and film
  - 1996 NEJM analysis of resuscitations on TV
    - Young, trauma victims (only 7/60 w/ chronic illness!)
    - 2/3rd cases successful resuscitation and discharge
    - Focus on “miracles”
  - 2006 study of elderly: 81% believed >50% chance
    of surviving inpatient CPR and leaving the hospital
  - Reality: ~ 15% of all persons survive to discharge

Code Status and Goals in the MICU
- Interviews of 100 patients/surrogates and their physicians in large academic, medical ICU
- Examined patient/surrogate knowledge of CPR, code status preferences, and goals of care
- Findings:
  - Few (4%) able to identify 3 main components of CPR
  - Average patient/surrogate predicted survival p-CPR = 72%
  - Notable mismatches between patient/surrogate and MDs:
    - CPR preferences vs. orders (16% mismatch)
    - Stated vs. perceived “most important goal” (68% mismatch)
Advanced Dementia: “Artistic License”...

Dementia: A Different Lens

Seeking Informed Consent

Video Decision Support Tool for Advance Care Planning in Dementia: Randomized Controlled Trial

- Study of 200 community elders, mean age = 75
- Examined impact on preferences for care: verbal narrative vs. verbal + video of video

<table>
<thead>
<tr>
<th>Prefer Life-Prolonging Care</th>
<th>Prefer &quot;Limited&quot; Care</th>
<th>Prefer Comfort Care</th>
<th>Unsure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Verbal</td>
<td>14%</td>
<td>19%</td>
<td>64%</td>
</tr>
<tr>
<td>Verbal + Video</td>
<td>4%</td>
<td>9%</td>
<td>86%</td>
</tr>
</tbody>
</table>

- Video group preferences more stable (5% change vs. 29% change at 6 weeks)

Volandes A et al. BMJ, 2009
“Dying is fundamentally a personal experience, not a set of medical problems to be solved.”

Ira Byock, MD

Kubler-Ross: Stages of Dying

- **Denial** (this isn't happening to me!)
- **Anger** (why is this happening to me?)
- **Bargaining** (I promise I'll be a better if...)
- **Depression** (I don't care anymore)
- **Acceptance** (I'm ready for whatever comes)

How well do we create “safe space” for genuine emotion?

Acceptance

The Fountain, 2006
Relationship and Closure

- I love you
- Please forgive me
- I forgive you
- Thank you

Sharing Our Words

The Sea Inside, 2004

Thoughts and Questions
(Enough Drama for One Day?)