Natural Death:
*Is it Even Possible Anymore?*

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Conflicts of Interest Slide

- No financial interests influenced this talk
- But...as you listen, it may be worth noting that
  - As a PC consultant at a tertiary care hospital it can be easy to view one’s role as conflict manager
  - And these experiences, likely did bias this talk!

Objectives

- Practice Based Learning and Improvement
  - Examine how natural death is conceptualized in the published medical literature.
- Medical Knowledge
  - Identify 5 chronic illnesses for which advances in life-prolonging therapies have significantly influenced the end-of-life decision-making process.
- Patient Care
  - Outline care strategies which will help our patients navigate the exhausting end-of-life decision-making process in the era of unnatural deaths.
Do clinicians want their patients to have a “natural death”? Do clinicians want their patients to have a “natural death”?

- I believe we do!
  - We are increasingly utilizing hospice in the hopes of fostering more natural deaths for our patients.
  - We aim to avoid “bad deaths”
    - We even measure chemo use; ER visits; CPR in last month of life utilized to assess the quality of EOL care.
  - Overuse of “aggressive” or “futile” care is the #1 cause of clinician moral distress especially in the ICU.
  - You hear it in our language: e.g. “Allow Natural Death” instead of DNR/DNI
Do cerebral bioethicists want to preserve the concept of a natural death?

• YES!
  – Without a definition of ‘natural death’ we will not be able to specify some rational limits to the aspirations of...research and the medical care that ought to be invested to keep people alive.
  – A concept of natural death is imperative for us to know what is reasonable to hope for; the alternative is both spiritual and psychological chaos.


So, what does end of life care look like today in the US?

First: We’re Getting Sicker

• Baby Boomers:
  – sicker than their predecessors, but also living long enough to develop multiple chronic and progressive illnesses.

  “Neither the medical system nor most seniors are prepared for the financial and emotional crisis ahead.”
Second: there’s tremendous variability in our health care systems

- **Dartmouth Atlas Report:**
  - Where you live is a bigger determinant on the aggressiveness of the end-of-life (EOL) care plan than the patient’s preference.
  - Geographic areas of increased aggressiveness →
    - More time seeing specialists during EOL
    - More days in the hospital
    - More likely to die in the ICU

**2014 IOM: Dying in America**

- EOL care has greatly intensified.
- Most Americans die in the hospital even though 80% of Americans wish to die at home.
- Even though the # of people receiving hospice care has increased since 1982, referrals for hospice happen later in the dying process.
  - Significant trend of referrals <3 days before death

**2014 IOM Dying In America Report**

- Why?
  - For most common chronic illnesses there are more targeted/less toxic life prolonging therapies available to patients.
  - Patients want access to these therapies
  - Clinicians/patients/family members have more of and more complex care decisions to make.
  - Hospice requirements that patients renounce curative care are increasingly seen as barriers.
Americans: You want EOL care options? YOU GOT IT!

EOL Care Options

- At the very least, our patients now need to make more active decisions to decline standard of care therapies to attain a more natural death.
- When active decisions are made to forgo medical therapies is that really a “natural death”?
- What are the emotional consequences of these decisions?
  - Guilt?
  - Exhaustion?
  - Patient/family discord?

How many times in the last year has a seriously ill patient said to you, “I wish I would just die in my sleep?”
Let’s Take a Tour of Some Common Medical Illnesses Today

Advanced Heart Failure

• Wider utilization of Ventricular Assist Devices, ECMO, Total Artificial Hearts, Intra-aortic balloon pumps, Heart Transplantation...

• Not only do patients who receive these therapies often live longer, but better.

• Consequently more AHF patients are being evaluated as candidates for these therapies

VAD Survival

Yet...

• Narrow window of opportunity for these advanced therapies

• Requires a degree of medical sophistication from the patient to be a good VAD candidate
  – Adequate social support, history of adherence with medical therapies, ability to learn new tasks

• Harsh realities remain
  – Only 1 in 12 referred patients are VAD candidates
  – If you don’t receive a VAD, 80% 1-year mortality on optimal med therapy for AHF
Furthermore...

- It’s not just the VAD, there’s other options to consider
  - Bi-V Pacemakers
  - Milrinone infusions
  - Implantable defibrillators
  - Beta blockers/Ace inhibitors/Statins
    - Firmly entrenched into cardiac definition of quality care
- Leads to more discussions about when to stop/deactivate cardiac therapies

- What’s the psychological effect of this on our patients and families?
  - Guilt or even embarrassment for those who decline or are declined for such therapies
  - More MD visits to be evaluated for such therapies
  - For rural patients, the option of a tertiary referral becomes standardized.
  - More reminders and regret of past behaviors or decisions.

What if they get a VAD?

- The case of Mr. C
- If a patient eventually decides to stop the VAD due to QOL concerns or medical complications, the transition point of care often occurs in the hospital.
- Why? Extensive informed consent discussions needed.
  - Anticoagulation?
  - Milrinone gtt?
  - Use of vasopressors?
  - When to turn off the VAD (home vs hospital)?
  - Pharmacologic care plan when VAD discontinued?
  - Code status?
  - Cardiac meds – diuretics?
  - Then once all that was settled...

VAD Care

- The case of Mr. C
  - If a patient decides to stop the VAD either due to QOL concerns or complications, the transition point often occurs in the hospital.
  - Why? Requires extensive informed consent discussions.
    - Anticoagulation?
    - Milrinone gtt?
    - Use of vasopressors?
    - When to turn off the VAD (home vs hospital)?
    - Pharmacologic care plan when VAD discontinued?
    - Code status?
    - Cardiac meds – diuretics?
    - Then once all that was settled...

  —Donate the VAD equipment after death: yes or no?
- Once that was settled...
Mr. C woke up!

And we had the same discussions all over again.

What happened to Mr. C?

- After 4 goals of care meetings involving the patient, family, PC, AHF, cardiology, RN, SW, nephrologist, neurologists, hospice team...
  - Discharged home.
  - VAD and milrinone gtt turned off that night
  - Died 1 day later with his family at bedside
  - Bereavement call 3 days post death:
    - Wife found solace that her husband died at home the way he said he wanted but...

Wife of Mr. C

“Everyone said this would be a way to help him die more naturally, but nothing about this felt natural.”

What about the home hospice team?

- They provided
  - Near round the clock specialized nursing care on a weekend for the patient
  - A hospital bed, Foley, oxygen, etc
  - Chaplain support
  - Milrinone gtt, IV tubing and poles
  - IV opioids and benzodiazepines
- And were reimbursed about $300.
Other Illness Trajectories: Respiratory

• Wider adoption and utilization of NIPPV and high flow oxygen systems
  – E.g. Bilevel support, Optiflow, Vapotherm
• More palliative options to consider.
• But also, can result in agonizing decisions of when to stop and disposition challenges of transitioning to home or hospice settings

Renal Disease

• From the 1990’s to mid 2000’s:
  – more Renal Replacement Therapy initiation in ages 80-85
• Why?
  – More reported cases of renal transplant successfully improving the lives of elderly patients.

Neurologic Illness

• Anoxic brain injury: hypothermia protocols
• Parkinson Disease: deep brain stimulators
• CVA: tPA, early interventional approaches
• Dementia: ...an example where the standard of care has shifted away from the standard use of “aggressive” therapies like artificial feeding tubes, nutrition, and hydration and more toward comfort care with illness-related dysphagia?

Dementia (cont’d)

• Yet, since 2003...
  – growing trend for NH residents to die in the hospital
• Growing trend for NH residents to suffer from a multitude of chronic, progressive illnesses in the last year of life and have less functional independence in the last 3 months of life.
  – Davies EA, Higginson IJ. WHO, 2004
What about Cancer?

“This ain’t your grandpa’s chemo anymore”

- Targeted systemic therapies, immunotherapies, CAR T Cell Therapies
- 20% reduction in mortality risk between 1991 and 2010. 2020?
- Systemic therapies are often much better tolerated and some can even be available as pills.
- This has led to a shifting role of chemotherapeutics as maintenance therapy.

Rising Survival & Cost in Cancer Care

5-Year Survival Rates (%)
All Cancer Types in US

<table>
<thead>
<tr>
<th>Year</th>
<th>Rate</th>
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<tbody>
<tr>
<td>1975-77</td>
<td>49%</td>
</tr>
<tr>
<td>1987-89</td>
<td>55%</td>
</tr>
<tr>
<td>2003-09</td>
<td>68%</td>
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Annual Direct Costs for Cancer Care

<table>
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<tr>
<th>Year</th>
<th>Cost</th>
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<tbody>
<tr>
<td>2006</td>
<td>$104 billion</td>
</tr>
<tr>
<td>2010</td>
<td>$138 billion</td>
</tr>
<tr>
<td>2020</td>
<td>$158-173 billion*</td>
</tr>
</tbody>
</table>

Mariotto AB, et al. JNCI 2011;103:1-12

But also..

- Significant increase in EOL health-care utilization:
  - ED visits/hospitalizations/ICU stays/systemic cancer therapy in the last weeks of life
  - Initiation of hospice services < 3 days before death

- By the time the transition to comfort care occurs,
  - Patients are more adapted to a cancer treatment milieu
  - Comfort care is a big change in normalcy
  - Sense of abandonment from oncology providers?

Why?

- There is prospective data, that as patients’ disease progresses and their care gets more complex,
  - They may be MORE likely to change their mind about dying at home.
“No Place Like the Hospital”

- Round the clock nursing care from some of the most talented/knowledgeable/compassionate EOL RNs in the US
- At your fingertip access to PC and other specialists
- Access to palliative interventions
  - XRT, palliative surgeries, infusions, optiflow, celiac plexus blocks
- Access to IV pharmacotherapies
- Access to SWs, chaplains
- Access to familiar specialists and clinicians.
- Private room
- No room and board fee
- High class chefs, massage therapists, music thanatologists!

Summary Points

- The concept of natural death...
  - Meaning you comfortably succumb to an underlying illness beyond one’s control at home
- is becoming a thing of the past.

If you want that “George Washington” death, then you must make strategic decisions to achieve it.

Speaking of George Washington

What do we do about this?

- Let’s reframe our concept of natural death.
  - Considering what’s involved, isn’t it now **natural** for human agency to be heavily intertwined with the dying process?

- Let’s accept our clinical role in complex shared decision-making regarding as part of the modern dying process.
Let’s reframe our concept of “natural death” to mean that:

• Medical care was accessible to our patients
• The medical care “fit” with the wider context of the person’s values, life, and illness.

What do we do about this?

• Acknowledge that our concept of a natural death may be different from the values of our patients.
• Advocate for more collaborative and novel care models for dying patients
  – Open-access hospice models or other unique care models that entwine comfort and life prolonging care.
  – As opposed to all or nothing care models

The evolving role of hospice

• Let’s recognize the wonderful care and support our patients families receive from hospice through grueling care transitions
• Hospice is uniquely designed to help patients get off the path of constant decision-making
• But
  – The current financial model of reimbursement is likely untenable for them considering the future growing complexities in EOL care.
• Growing trend of hospice care coming to the hospital?

Evolving Role of the PC Clinicians

• Fortunately now, in many hospitals, we’re hear to help!
• But we also need your help.
• We’re no substitute for a good primary team.
The Evolving Role of Internists

- Hospitalists likely will be intertwined with EOL decision-making:
  - When to withdraw life sustaining treatments, Leading goals of care meetings, etc.
- PCPs, less involved?
- Growing need for hospitalists to attain core palliative care skills – communication during a medical crisis, hospice awareness, prognostication, etc.
- Growing need for hospitalists to “go out on a limb” – Offering guidance and recommendations even when we may not be 100% certain what’s the right thing to do.

Subway Sandwich Model For EOL Care

“I DON’T KNOW.
YOU’RE THE SANDWICH GUY.
YOU TELL ME WHAT I SHOULD HAVE.”

References

-9/17/18