Why YOU Are Key to End of Life Care Decisions

Gary S. Lee, M.D.
Assistant Director, Palliative Care Service
Santa Clara Valley Medical Center
Mrs. S

- 88 year old woman with critical AS, CAD
- Refused surgery in past, now inoperable
- Lives with family, still functional
- Orthopnea, reduced exercise tolerance
- Elevated neck veins, clear lungs, no edema
- Maximal medical therapy
- Has not completed advance directive
Outline

• An Overview of Dying in America
• Why End of Life Care is Suboptimal
• Starting ‘The Conversation’
• Advance Directives and POLST
• Cultural and Spiritual Issues
## Top Five Causes of Death

<table>
<thead>
<tr>
<th>Year</th>
<th>Influenza, pneumonia</th>
<th>Tuberculosis</th>
<th>Gastritis, enteritis</th>
<th>Heart Disease</th>
<th>Stroke</th>
</tr>
</thead>
<tbody>
<tr>
<td>1900</td>
<td>11.8%</td>
<td>11.3%</td>
<td>8.3%</td>
<td>8.0%</td>
<td>6.2%</td>
</tr>
<tr>
<td>2005</td>
<td>Heart Disease</td>
<td>Cancer</td>
<td>Stroke</td>
<td>COPD</td>
<td>Accidents</td>
</tr>
<tr>
<td></td>
<td>26%</td>
<td>23%</td>
<td>6%</td>
<td>5%</td>
<td>4%</td>
</tr>
</tbody>
</table>

Brim et al., 1970

National Center for Health Statistics
How We Die

• 90% of deaths chronic disease
• 10% of deaths sudden death or rapid decline
Patterns of Functional Decline
Where We Die

- 90% prefer to die at home
- 50% die in hospital
- 23% die in nursing facilities
- 23% die at home
Satisfaction with Care

• Institutional death
  – Unmet needs
  – Poor communication
  – Lack of support and respect

• Death at home with hospice
  – Higher satisfaction
  – Fewer concerns with care

(Teno, 2004)
Important Factors

- Physical
- Spiritual
- Preparation for the end
- Psychosocial
Key Points

• Causes of death have changed
• Most deaths follow chronic disease
• Care of the dying is less than optimal (institutional, associated with pain/suffering)
Why is end of life care less than optimal?
Why is end of life care less than optimal?

- “The most avoided conversation in America” (Pauline Chen, MD)
- Institutional glide path (Joanne Lynn, MD)
Do Patients Want to Talk

• Prognosis
  – Almost all want qualitative information
  – Balance hope and realism, honesty and ambiguity

• Advance Directives
  – 95% thought worthwhile (after having a discussion)

• Spirituality
Physician Factors

• Unaware of patient preferences
  – 47% know when pt doesn’t want CPR (SUPPORT)

• Lack of communication skills (Tulsky, 1998)
  – 5.6 minute conversation
    – MD spoke 3.9 minutes

• Uncertainty about prognosis
Benefits of End of Life Conversations

• Patients (Wright, 2008)
  – Less aggressive care, earlier hospice
  – Better quality of death
  – No increase in worry or depression

• Caregivers
  – Less depression, better QOL

• Physicians (Jackson, 2008)
  – Closer relationship to patient
  – Better job satisfaction

• System: less cost (Zhang, 2009)
Key Points

• We don’t want to talk about it
• We’re not very good at talking
• Talking has benefits to patients, caregivers, and ourselves
The Conversation

- Which patients
- Initiating and guiding the conversation
- Words or topics to avoid
- Goals
- Barriers
Who Should We Talk With

• Elderly
• Serious, chronic illness
  – CHF
  – COPD
  – Dementia
  – CKD
  – Cirrhosis
• Multiple hospitalizations, recent discharge
• ‘would you be surprised if…’
• Other opportunities
Initiating the Conversation

• Assess patient’s understanding
  – how do feel things are going, or
  – have you given any thought to how you wish to be cared for should your illness worsen?

• Explain the rationale
  – I want to talk with you about plans for your future care
  – I’d like to spend some time talking to you about the future course of your illness so that I have a clear understanding of your wishes
Topics to Cover

- Decision-maker: Identify a surrogate
- Disclosure: Patient’s preferences for receiving and sharing information
- Delight: What gives meaning and value to patient’s life
Words to Avoid…

• “there is nothing more to do”
• “do you want us to do everything?”
• “you have failed…” or “are failing…” (treatment)
• “withdrawal of care”
Communication Tips

• Use empathy
• Respond to emotion
• Allow sufficient time
• Avoid medical jargon
• Use positive language
• Clarify ambiguous terms (‘burden’, ‘vegetable’)
Barriers to Communication

- Time
- Language/Cultural Barriers
- Training
How Much Time?

• Expert Conversations
  – Audiotaped discussions by expert authors
  – Less verbally dominant
  – Mean 14 vs. 8 minutes
  – Less information about treatments, procedures
  – More psychosocial, lifestyle discussion
Key Points

• Have the discussion with selected patients
• Take your time (may need more than one visit)
• Focus more on values than on specific procedures
Advance Directives and POLST

- Emphasize the discussion, not the document
- Living will
- Durable power of attorney for health care (DPAHC)
- Physician Order for Life Sustaining Treatment (POLST)
Advance Directives

• Result of Patient Self Determination Act, 1990
• Desire to avoid painful, prolonged death
• Fear of overtreatment
• Allow exercise of autonomy when capacity is lost
Living Wills

• Specifies what treatments are desired
• Usually standard language
• Often very specific
  – Permanent unconsciousness
  – Incurable, irreversible condition close to death
DPAHC

- Names a health care agent
- Activated at time of incapacity
- Can be activated immediately
- Power to make almost all health care decisions
- Allows individuals to be disqualified
- No hierarchy in Calif. if no directive
Advance Directive Positives

• Allow the patient’s voice to be heard when they lack decisional capacity, promote autonomy

• Good features:
  – Promote patients’ understanding of their values, goals, and preferences
  – Serve as a basis for discussion with proxy
Limits of Advance Directives

- Not completed
- Not available in medical record
- Provider unaware of document
- Inaccurately predict future preferences
- Fail to apply to specific circumstances
- Inaccuracy of proxy decision maker
- Fail to alter clinician behavior
- DNR misinterpreted as comfort care
POLST

• Signed medical orders
• Addresses range of life-sustaining interventions
• Allows for choosing or foregoing treatment
• Brightly colored, clearly identifiable, standardized form
• Recognized and honored across all treatment settings
CA AB 3000 (Wolk)

- Does not mandate use of form
- Requires form be honored
  - Unless new orders issued
- Requires
  - Physician signature
  - Patient or surrogate signature
- Provides immunity
Advance Directives vs. POLST

• Advance Directive
  – For every adult
  – Requires decisions about myriad future treatments
  – Clear statement of preferences
  – Needs to be retrieved
  – Requires interpretation

• POLST
  – For the seriously ill
  – Decision among presented options
  – Checking of preferred boxes
  – Stays with the patient
  – Actionable medical order
Evidence Supporting POLST

- Hospices
  - 96% DNR
  - 78% want more than lowest level of Rx
  - Preferences honored 98% of time
- Nursing facilities
  - 88% DNR
  - 77% want more than lowest level of Rx
- EMTs find form useful
- PACE Program: care matched POLST instructions 80-90%
Key Points

• The document is only as good as the discussion that produced it
• Advance directives should be encouraged, but be aware of limits
• Consider using POLST
True or False?

- Non-white patients are less likely to complete advance directives
- African Americans are more likely to desire aggressive treatment
- Asian Americans are more likely to make decisions as a family
True or False?

Doctors …
• are more likely to play golf on Wednesdays
• are likely to interrupt patients in less than 18 seconds
• believe in ‘doing something’ even if there is little data to support it
Cultural Barriers

• Every encounter is cross cultural
• Large diversity *within* cultural groups
• Stereotypes vs. generalizations
## San Mateo County Census

<table>
<thead>
<tr>
<th>Race</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>White, not Hispanic</td>
<td>46%</td>
</tr>
<tr>
<td>Latino</td>
<td>23%</td>
</tr>
<tr>
<td>Asian</td>
<td>24%</td>
</tr>
<tr>
<td>Black</td>
<td>3.3%</td>
</tr>
<tr>
<td>Two or more races</td>
<td>3.2%</td>
</tr>
</tbody>
</table>
SM County, Languages

Foreign Born 32%
Language other than English at home 41.5%
Speak English less than ‘very well’ 18.5%
Culture and End of Life Care

- Culture bubbles to the surface
- Autonomy vs. beneficence
- Definition of family
- Gender roles
- Care of the elderly
- Power
- Communication patterns
- Language
Common Conflicts

• Communicating bad news
• Locus of decision making
• Attitudes towards advance directives
Cross-Cultural Skills

- Self awareness
- Active listening
- Bearing witness
- Cultural humility
Recommendations

- Ask patient centered questions
- Work with professional interpreters
- Follow patient’s preferences where possible
Summary

• Better end of life care is desperately needed
• YOU can make a difference by starting the conversation
• Time and culture are surmountable challenges