Honoring Choices: An Advance Care Planning Model

Robin C. Cummings
Honoring Choices Virginia

Ken Faulkner
VCU Health

Rebecca A. Gruszkos
Bon Secours
Objectives

1. Describe the relationship of Advance Care Planning to Patient Safety and Patient Experience
2. Share experiences learned from implementing an advance care planning model
3. Articulate the mission of Honoring Choices® Virginia
“Researchers find that the mortality rate holds steady at 100%.”

The Onion News Network
“I’m not afraid of dying. I just don’t want to be there when it happens.”

Woody Allen
The Patient Self Determination Act

Federal law (passed in 1991) requiring all health care organizations receiving Medicare or Medicaid funds to do the following:

• Inform patients of their right to accept or refuse health care using written information.
• Ask patients if they have advance directives or would like information on advance directives.
• Document that patient has an advance directive.
• Cannot discriminate against patients who do not choose to have an advance directive.
Elements of Advance Directives

- **Living wills**: Written statement on preferences for end of life treatment usually addressing restrictions on undesired life-sustaining interventions.

- **Appointment of surrogate decision-makers (aka “Agents”)**: Specific naming of an individual(s) to make decisions and implement patient wishes if the patient is incapacitated.

- **Additional directives**: Organ donation, donation for research/anatomical study, mental health care provisions, provisions for pregnancy
Virginia Advance Directives: The Living Will

• Written instructions for treatment in case of “imminent death” or “unaware of self or surroundings” (persistent vegetative state)

• Allows for the withdrawal of life-prolonging therapy

• You may also direct which treatments should be provided (“within the limits of generally accepted health care standards”)
Virginia Advance Directives: Agent for Health Care Decisions

• May appoint primary and successor agent to make decisions when you are not able to communicate your wishes

• Your agent may give consent or refusal for treatment, may hire or discharge medical providers, may review records and receive medical information, etc.

• Agent’s authority ends with the patient’s death or if patient recovers and can communicate

• Scope of the powers of the agent are determined by you

• Agent’s powers *do not* include financial power of attorney. (If needed that is done separately with a lawyer.)
Who decides if you don’t choose an agent?

1. Legally appointed guardian
2. Patient’s spouse (except where divorce action has been filed)
3. Adult child
4. Parent of patient
5. Adult sibling
6. Any blood relative in descending order of relationship
Agent to make anatomical gift

- You may authorize organ and tissue donation for transplantation
- You may donate your body for medical research or instruction

Can’t do both, must select one or the other.
Advance Directives: Successes

• Written instructions for end of life wishes and preferred treatment
• Appointment of surrogate spokesperson and decision maker
• Backing of state and federal law
• Work best as a product of extensive reflection and conversation
The “Underachieving” Advance Directive: Weaknesses

- Underutilized – 47% of adults > 40
  (*Dying in America* report, IOM, 2013)
- Many forms are vague, lack specificity or are unclear
- Challenges with storage, access, and retrieval of documents
- Appointed surrogate may or may not truly understand the preferences of the patient
- Despite legal backing may be ignored or overridden
- Health care providers lack understanding, time, skill and/or are uncomfortable with EOL discussions
Shared Values and Philosophy of Life

All persons, regardless of their medical or physical condition, possess inherent dignity and are worthy of respect, protection, and care.

Many faith traditions believe human life is a sacred gift from God.

HOWEVER...

Respect for human dignity and human life ≠ must do everything possible to prolong physical life when death is inevitable.
Non-beneficial Treatment

A provider also does not have to follow a directive that asks for *inappropriate or non-beneficial treatment* that would offer little or no benefit.

Not all Treatments that prolong biological life are beneficial to the patient.

More ≠ Better
How can we avoid non-beneficial Tx?

- Informed consent discussions in advance of the crisis or EOL scenario
- What ethical principles are we supporting in this process?

**Autonomy**

**Beneficence** (do good, be of benefit)

**Non-maleficence** (do no harm)
Case Example 1

- 80 year old female arrives in ED from local SNF. Is unresponsive, no family present
- AMD is located in EMR. The only section completed is Appointment of Healthcare Agent. Staff contacts a nephew who is listed as the sole agent on the directive
- Nephew is unaware of appointment as healthcare agent and says he is not comfortable making medical decisions. He recommends his sister to be the Pt’s agent instead
What was missing from the ACP process?

• What must the hospital do next?

• Could this happen in your setting?
Case Example 2

• 78 yr old female with ESRD on dialysis. For past year, has had documented dx of mild dementia. Has 3 daughters who are consistently in conflict with one another. Pt resides in the home of one of these daughters

• During last hospital admission, Pt completed an AMD, appointing her granddaughter as sole agent, and indicating her wish not to prolong the dying process in the event of terminal illness or neurological impairment
Case Example 2, Cont.

• Pt is now re-hospitalized with acute infection and new complications that significantly reduce her tolerance for dialysis. Patient is declining rapidly and can no longer participate in medical decision making. Attending MD contacts granddaughter who agrees to a hospice referral.

• 3 daughters visit hospital daily and do not understand why the medical team isn’t communicating with them about Mom’s care. They are informed that the granddaughter is the healthcare agent. They ask to see the document.
Case Example 2, Cont.

- Daughters read mother’s wishes about not prolonging the dying process. They question the validity of the entire document, referencing mom’s mild dementia—”she didn’t understand what she was saying”.

- Nephrologist now hesitates on hospice referral and questions whether dialysis should be back on the table. Calls a palliative consult for help
What Went Wrong?
Legal/Policy

• The authority of the healthcare agent appointed in an advance directive outweighs that of any other surrogates (even spouse or other Next of Kin)

• It is an offense to alter, conceal, or destroy advance directives (only the individual who executes the directive may change or revoke)

• “Physician Aid in Dying” (Physician-Assisted Death) is prohibited in most states, by law
Traditional Assumptions

• Advance directives are only used to limit medical interventions
• Must have a statutory form or assistance from an attorney in order for an advance directive to be legally valid
• Healthcare agent, spouse, or next of kin may overturn ACP documents (e.g. advance directive, Durable Do Not Resuscitate order) when patient loses capacity
• In absence of a healthcare agent or spouse, the eldest child is the authorized decision maker
Common Approaches to Decision Making

• “If your/the patient’s heart stops do you want us to do everything?” (does not constitute informed consent)

• Provider asks agent/next of kin: “What do you want us to do?” (surrogate burden)
Surrogate Decision Making Standards

Strongest: **Subjective**-- Makes Tx decisions based upon what the patient chose before losing capacity (Direct Conversation or Advance Directive)

Next Best: **Substituted Judgment**-- “If she could meaningfully respond to the current choice, what would she say?” (based on beliefs, values)

**Best Interest**: Benefit vs burden, risks vs benefits (What would be best under the circumstances)
How are we supporting ethical principles and promoting strong surrogate decision making?
Honoring Choices® Virginia

We believe that part of living well includes planning for an unexpected medical crisis so that your wishes, values and goals can be honored by your medical team and loved ones.

It can be difficult to know how to take the first step. We are here to help make that journey possible.
Key elements for sustainability

1. **System Redesign**
   - ACP team and workflows
   - ACP document
   - Storage & retrieval

2. **ACP Education & Facilitator Certification**
   - ACP Facilitator training
   - ACP team education
   - Other stakeholder education

3. **Community Engagement**
   - Materials that engage
   - Strategies to engage
   - Special population groups

4. **Continuous Quality Improvement**
   - The Five Promises
   - Implementation project plan
   - Ongoing QI plan

(Hammes & Briggs, 2011)
Promise #1: We will initiate the conversation

Promise #2: We will provide assistance with advance care planning

Promise #3: We will make sure plans are clear

Promise #4: We will maintain and retrieve plans

Promise #5: We will appropriately follow plans
- West End Internal Medicine
- Primary Healthcare Associates
- Palliative Medicine Clinic

- Infusion Centers and Cardiopulmonary Rehab @ Henrico Doctor’s Hospital Forest & Parham, Retreat
- Radiation Oncology @ HDH Forest Retreat Hospital

- Parkinson’s & Movement Disorder Clinic
- Physical Medicine & Outpatient Rehab Center for Advanced Health Management

- BSHS Memorial Medical Center
- Patterson Avenue Family Practice Medical Oncology, St. Francis

- Inpatient Rehab @ Chippenham & Johnston-Willis
- Employees & volunteers @ Chippenham & Johnston-Willis

- Nelson Clinic Family Practice
- VCUHS House Calls
- VCU Virginia Coordinated Care Complex Care Medical Home
Stages of Advance Care Planning Over an Individual’s Lifetime

**First Steps®**
Create an AD that identifies healthcare agent and goals of care for permanent brain injury

**Next Steps**
Identify goals of care, if illness complications result in “bad outcomes”

**Last Steps®**
Identify goals of care, expressed as medical orders using POLST paradigm

Healthy adults or those who have not planned

Individuals with advanced illness, complications, frequent encounters

Individuals whom it would not be a surprise if they died in the next 12 months

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The process of planning

Advance care planning is a *process* of planning for future medical decisions

- **Reflection** on goals, values, and beliefs (including cultural, religious, spiritual and personal)
- **Understanding** of possible future situations and decisions
- **Discussion** of these reflections and decisions with those who might need to carry out the plan
• Add video – Paul & Jean’s facilitated conversation (6 min)
The Gundersen Experience

• Reduced fragmentation through creation and communication of patient-centered plans
• Improved patient care and patient satisfaction by aligning treatment with individual goals and values
• Improved population health through enabling care coordination and community-wide planning
• Reduced per-capita costs stemming from unwanted care and treatment
# Cost of Care in the Last Two Years of Life

<table>
<thead>
<tr>
<th>Hospital</th>
<th>Inpatient Days per Descendent Last 2 Years of Life, 2010</th>
<th>Total Medicare Reimbursement of Care/Patient Last 2 Years of Life, 2010</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gundersen Health System</td>
<td>9.7</td>
<td>$48,771</td>
</tr>
<tr>
<td>University of Wisconsin</td>
<td>18.9</td>
<td>$67,734</td>
</tr>
<tr>
<td>Cleveland Clinic</td>
<td>25.5</td>
<td>$86,279</td>
</tr>
<tr>
<td>Mayo Clinic</td>
<td>17.5</td>
<td>$72,444</td>
</tr>
<tr>
<td>UCLA</td>
<td>28.5</td>
<td>$137,248</td>
</tr>
<tr>
<td>New York Univ. Medical Center</td>
<td>32.3</td>
<td>$131,624</td>
</tr>
<tr>
<td>National Average</td>
<td>14.4</td>
<td>$58,886</td>
</tr>
<tr>
<td>10th Percentile</td>
<td>14.4</td>
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</table>

Source: Based on 2010 Dartmouth Atlas Study Methodology. The Dartmouth Atlas methodology examines hospital inpatient care for the last two years of a Medicare patient’s life.
# Lessons learned and challenges ahead

<table>
<thead>
<tr>
<th>We learned...</th>
<th>Question for you...</th>
</tr>
</thead>
<tbody>
<tr>
<td>People in part-time roles were soon dealing with full-time responsibilities</td>
<td>Is your institution committing appropriate FTEs?</td>
</tr>
<tr>
<td>Not knowing what settings are best until you try them</td>
<td>Can you tolerate mixed results?</td>
</tr>
<tr>
<td>Some people trained as facilitators left their positions</td>
<td>Are you prepared to train more facilitators than you think you need?</td>
</tr>
<tr>
<td>Front-line folks can be overwhelmed by measurement tasks</td>
<td>Are you balancing your measurement demands with other duties and priorities?</td>
</tr>
<tr>
<td>Physician support drives referrals; physician resistance prevents referrals</td>
<td>Are you prepared to invest time and effort to get and maintain physician support?</td>
</tr>
</tbody>
</table>
Lessons learned and challenges ahead

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<tr>
<td>Must be a long-term priority of the executives of the sponsoring health system</td>
<td>Are your leaders aware of the upfront efforts needed to produce results in the long term?</td>
</tr>
<tr>
<td>Outcomes may take years to generate</td>
<td>Are your stakeholders able to commit long-term?</td>
</tr>
<tr>
<td>EMR challenges within and across providers and settings</td>
<td>Are there shared resources that can resolve this barrier to information sharing?</td>
</tr>
<tr>
<td>Community engagement takes a lot of field work</td>
<td>Who are your partners in the community?</td>
</tr>
<tr>
<td>State-level challenges impact growth (e.g., who can assist with ACP, Virginia’s legalistic model advance directive form)</td>
<td>What creative approaches can help with these challenges?</td>
</tr>
</tbody>
</table>
Questions and observations?

For more information:

www.honoringchoices-va.org