Advanced Care Planning: Are Goals of Care Discussions Timely?

Presenter
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Disclaimer

I have nothing to disclose
OBJECTIVES:

At the conclusion of this presentation participants will be able to:

1. Describe heart failure pathology and trajectory of care
2. Explain elements of advanced care planning
3. Describe barriers to advanced care planning for African Americans
Heart Failure [HF] in US

Source: AHA Heart Disease & Stroke Statistics

- Prevalence = 5,700,000
- Incidence = 670,000
- HF mention on one in 9 death certificates
- 50% death rate within 5 years
- Common diagnosis for persons > age 65
- High number of hospital discharges
  - 2007 = 990,000
- Hypertension
  - H/O HTH 75% of the time
  - Lifetime risk doubles with blood pressure > 160/90
- 8 – 10 fold increased risk after MI
- $39 Billion annual expenditures
Putting A Face To Heart Disease
HF In African Americans

• Advances in heart failure treatment have not necessarily translated into equity in improved outcomes for African Americans.

  – higher prevalence, especially at younger ages; more-adverse course with more frequent hospitalizations; and higher mortality rates compared to the general population. (Mitchell, Ferdinand 2011)
  – despite this distinct disease profile, remarkably underrepresented in large heart failure trials.
  – more often have a history of hypertension, renal insufficiency, and diabetes (Mitchell, Ferdinand 2011)
  – greater functional decline (Vaccairo et al 2002)
  – almost 50% higher risk of either death (Vaccairo et al 2002)

About HF

• HF is
  – A progressive syndrome with high mortality risk
• HF is not
  – Curable
• HF may develop from
  – Things we can change
• Patients may feel
  – Short of breath, Tired, Defeated
Common Heart Failure Presentations

**Systolic Dysfunction**

- Stretch – Remodelling
  - 3rd heart sound
  - JVD
  - Enlarged heart on CXR
  - EF < 40%
  - Pulmonary rales
  - Peripheral edema

**Diastolic Dysfunction**

- No Stretch – No remodelling
  - Heart muscle thickens and becomes stiff
  - Can not relax between contractions
  - Poor ventricular filling
  - EF > 40%
HF Described

• Heart muscle decline
  – AHA Stages A, B, C, D

• Activity tolerance
  – NYHA Functional Classes I, II, III, IV
Some Thoughts on HF

• Existing therapies slow disease progression.
• As a result, the prevalence of symptomatic heart failure has increased.
• Patients have ...........
  – More hospitalizations
  – More treatment options to help live longer; higher cost
  – More symptoms limit daily life
  – Health literacy concerns
  – The need for advanced care planning
HF Trajectory
Hallmark of care: Symptom Management

Typical Heart Failure Trajectory*

Health Status

Decline: Slow, progressive, varied duration

Crisis

Death

Time

Expectations for the Future

• Pay attention to the clinical trajectory.
• Predictive models offer uncertainties in estimates of survival.
• Difficult discussions now will simplify difficult decisions in the future.
• Uncertainty is inevitable and should be included in discussions with patients and family.

Allen, Stevenon et al 2012
Its Complicated
Prognosis is not only about expectations for survival.


Costs/Burden
Direct Medical Costs
Indirect Costs
Lost Opportunities
Caregiver Burden

Outcomes Relevant to an Individual Patient

Quality of Life
Symptoms
Physical Function
Mental
Emotional
Social

Survival
~ How do we know when we are prolonging life or prolonging death ~
Dedication

• To my immediate family members who passed too soon as a result of complications from chronic diseases
  – Where there goals of care and advanced care planning?

Jenn 56 Cancer
Nessa 41 HF

NO
• Death is a natural event in the cycle of life.
• Examining our own beliefs about life, death and dying is necessary.
• Helping patients live abundantly means helping them die with dignity, respect and the opportunity to fully participate in their own care.
Global Advanced Planning
2008 The Heart Failure Clinic: A consensus statement of HFSA

• Components
  – Shared knowledge: Incorporating into practice with care team
  – Ongoing care: discussions into the longitudinal care of HF patients
  – Patient referrals: referring to other professionals and resources for assistance
  – Documentation: recording the information
Global Advanced Planning

- Planning includes establishing the goals of care
- Clarifying acceptable treatment options (including discussions regarding palliative care and hospice)
- Determining where a patient wishes to spend the final days of life.

www.cancer.gov/cancertopics/pdq/supportivecare/lasthours
**Advanced Care Planning (ACPs)**

2008 The Heart Failure Clinic: A consensus statement of HFSA

**Rationale:** providers can improve patient/family satisfaction, provide compassionate care at the end of life that is in accordance with the patient’s wishes.

**Description:**

- Seriously ill patients or those with chronic illness with risk of mortality should be approached by their provider before near terminal
- Map out medical & nonmedical care before patient is unable to express wishes
- ACPs address challenges of living with chronic illness, complications and treatment options
  - Code status/living will/power of attorney
  - Device deactivation
  - CPR
  - Invasive procedures, surgery and hospitalizations
Advanced Care Planning (ACPs)

2008 The Heart Failure Clinic: A consensus statement of HFSA

• Cardinal feature of ACPs
  – Living will
  – Health care proxy
  – Durable power of attorney for healthcare
  – May be oral or written
  – May name a surrogate to make medical decisions
Palliative vs. Hospice

• Palliative
  – An active process involving patient/significant others, & interdisciplinary team to support life sustaining and end of life symptom management.

• Hospice
  – A passive process that provides comfort and support to patients/families at end of life.
Consumer Awareness About Palliative Care

## Biggest Concern for Patients with Serious Illness

<table>
<thead>
<tr>
<th>Concern</th>
<th>Percentage</th>
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</thead>
<tbody>
<tr>
<td>Doctors might not provide all of the treatment options or choices available</td>
<td>58%</td>
</tr>
<tr>
<td>Doctors might not talk and share information with each other</td>
<td>55%</td>
</tr>
<tr>
<td>Doctors might not choose the best treatment option for a seriously ill patient’s medical condition</td>
<td>54%</td>
</tr>
<tr>
<td>Patients with serious illness and their families leave a doctor’s office or hospital feeling unsure about what they are supposed to do when they get home</td>
<td>51%</td>
</tr>
<tr>
<td>Patients with serious illness and their families do not have enough control over their treatment options</td>
<td>51%</td>
</tr>
<tr>
<td>Doctors do not spend enough time talking with and listening to patients and their families</td>
<td>50%</td>
</tr>
</tbody>
</table>

Life Sustaining vs. Palliative vs. Hospice

“There is nothing else we can do for you?”
Figure 1. Palliative care integrative model.
Today, about 30% of Americans have shared these important discussions and completed documents.
Missed opportunities for advance care planning communication during outpatient clinic visits

• Early provider-patient communication about future care is critical for patients with heart failure (HF).

• However, ACP discussions are often avoided.

• Or occur too late to usefully inform care over the course of the disease.

Timing of Discussions

• Decision reversal after discharge is not uncommon. *(Krumholz, Phillips et al 1998)*

• Most patients and families want accurate and honest conversations with their clinicians. *(Apatria, Boyd et al, 2008)*

• Doctors and nurses share this responsibility.
Studies show that……..

- Advance care discussions are initiated late in the course of illness.
- Resuscitation status orders are documented near the time of death.
- Advance care discussions are suboptimal and lead to dissatisfaction with the process.
- When these discussions do not take place and plans are not made, the final hours may be filled with suffering and distress.

Contro, Larson et al 2002; Burns, Griffin et al 2001; Wolfe Grier et al 2000

Quality Outcomes

• Patients who reported having end-of-life discussions with their physicians had significantly lower health care costs. Higher costs were associated with worse quality of life at death. (Zhang, Wright et al 2009)

• Aggressive care was associated with worse patient quality of life and caregiver adjustment. (Wright AA, Zhang B, Ray A, et al 2008)

• Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. (JAMA 300 (14): 1665-73, 2008)

• In a cross-sectional study of parents who lost a child to cancer, clear discussions between the primary oncologist and the parents were more likely to be associated with planning for the location of death, fewer hospital admissions, and parents feeling more prepared for the child's end of life (Dussel, Kreicbergs, et al 2009)
Cultural beliefs and values are thought to account for differences between African Americans and whites in the use of advance directives and beliefs about hospice care, but few data clarify which beliefs and values explain these differences. Two hundred five adults aged 65 and older who received primary care in the Duke University Health System were surveyed. The survey included five scales: Hospice Beliefs and Attitudes, Preferences for Care, Spirituality, Healthcare System Distrust, and Beliefs About Dying and Advance Care Planning. African Americans were less likely than white subjects to have completed an advance directive ($35.5\%$ vs. $74.4\%$, $p < .001$), and held fewer palliative beliefs. Key words: race; end-of-life care; hospice; advance directives

Cultural beliefs are central to perceptions of illness and may influence healthcare utilization. As such, understanding how culture affects healthcare is essential to efforts...
Cultural Beliefs and Values

African Americans………

• Cultural beliefs and **values** account for differences among African Americans in the use of ACD & hospice
  – African Americans were less likely to have completed an advance directive and had **less favorable beliefs** about hospice care.

• More likely to express **discomfort** discussing death, want aggressive care at the end of life, have spiritual beliefs that conflict with the goals of palliative care and distrust the healthcare system.

  (Johnson, Kuchibhatla & Tulsky, 2008)
Cultural Belief & Values

• African-Americans

  – Generally acceptable to withhold or withdraw life-support, but were the most likely to want to be kept alive on life-support.

  – Have a deep distrust towards the health care system and a fear that health care was based on one's ability to pay.

Blackhall, Frank etal (1999)
Limitations of Cognition, Literacy, and Numeracy

Steward, Weomtraub et al, 2010

• Patients have a poor understanding of their medical interventions and that their preferences are not driving decisions.

• A survey of 3010 adults revealed lack of knowledge of 9 common medical conditions.
  – In the case of ICDs, more than half of patients overrated the benefits of ICD therapy by 500%, thinking that >50 of 100 lives would be saved by the ICD therapy over the next 5 years (the actual estimate is closer to 5–10 per 100).
Communication Challenge

• 40- 80% of medical information is *immediately* forgotten

• Almost half of information is remembered *incorrectly*

• The more information given, the more information forgotten

Impact of Low Literacy on Health

• Adults with low health literacy:
  – Are often less likely to adhere to prescribed treatment and self-care regimens
  – Make more medication or treatment errors
  – Fail to seek preventive care
  – Are at a higher risk for hospitalization than people with adequate literacy skills
  – Remain in hospital nearly 2 days longer
  – Utilize more treatment

How Health Professionals Can Help in the Clinical Setting

– Quickly identify patients with low literacy levels
– Ask patients to explain your instructions (teach back method) or demonstrate the procedure
– Use proven communication strategies
Clues in the Clinical Setting

• Registration and other forms filled out incompletely or incorrectly.
• Written materials handed to a relative or other person accompanying the patient.
• "I will read this at home."
• "I can't read this now; I forgot my glasses."
• Aloofness or withdrawal during physician/provider explanations.
• Frequently misses appointments
• Frequent errors in medications or self-care instructions, and consequently considered "noncompliant."
ACP in African Americans

Perceptions among African Americans

• "If I don’t acknowledge that I need a living will or durable power of attorney for health care, then I’m alright. If I do, then that means I need it."

• Request aggressive medical treatment at the end of life even when it is unlikely that such treatment will improve outcomes.
  – May be linked to historical mistrust and negative experiences with healthcare systems
  – Or, the patient’s mistaken belief that any option that fails to include aggressive treatment is a breach of the standard of care to which the patient feels legally entitled.

(Perkins, Geppert et al. 2002)
Most African Americans Believed…. 

- That “the health system controls treatment,” few trusted the system “to serve patients well,” and most believed they should “wait until very sick to express treatment wishes.” (Perkins, Geppert et al 2002)
Some Reason Why African Americans Might Not Use ACP

• Confusing legal terminology and are difficult to understand.
• Lack of awareness of end of life treatment options.
• Communication styles of healthcare workers.
• Lack of trust.

(Perkins, Geppert et al. 2002)
Many African Americans view advance care planning as "giving up hope."

(Perkins, Geppert et al. 2002)
Five Steps for Successful Advance Care Planning

Step 1: Introduce the topic
Step 2: Engage in Semi-Structured Discussion
Step 3: Document patient preferences
Step 4: Review and update the directive
Step 5: Apply the directive to actual circumstances

One useful mnemonic device that can help clinicians respond empathetically in conversations is the mnemonic **N-U-R-S-E**

### Table 8.

Using the N–U–R–S–E Mnemonic to Help Express Verbal Empathy When Communicating With Patients With Advanced Heart Disease

<table>
<thead>
<tr>
<th>Technique</th>
<th>Sample Language</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name the emotion</td>
<td>You seem worried about what will happen if we don't implant the LVAD. Can you tell me more about that?</td>
</tr>
<tr>
<td>Understand the emotion</td>
<td>I see why you might be fearful of proceeding with the transplant. Can you help me understand what you're afraid of?</td>
</tr>
<tr>
<td>Respect the emotion</td>
<td>You have shown a lot of strength up to this point. Tell me more about what keeps you going</td>
</tr>
<tr>
<td>Support the patient</td>
<td>Whether or not you choose to have the procedure, I want you to know that I will continue to be your cardiologist and will take care of you no matter what happens</td>
</tr>
<tr>
<td>Explore the emotion</td>
<td>You mentioned earlier that you're concerned about what this worsening of your shortness of breath might mean. Can you tell me more about your concerns?</td>
</tr>
</tbody>
</table>
Advance Care Planning

The Heart Failure Society of America (HFSA) is a non-profit organization of health care professionals and researchers who are dedicated to enhancing quality and duration of life for patients with heart failure and preventing the condition in those at risk. These educational modules have been developed to help patients, their families, and individuals at risk for heart failure understand and cope with the disease. For more information about the Society please visit our web site www.hfsa.org.

www.hfsa.org

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Introduction

This module will provide information on:
- Advance care plan components.
- The importance of an advance care plan.
- Making an advance care plan.
- What to do with your advance care plan.
- Care choices.
- Changing your mind.

It will help you:
- Understand the purpose of an advance care plan.
- Make your own advance care plan.
- Understand what to do with your advance care plan.
- Involve your family, friends, health care providers, and other advisors such as a lawyer in your plans for future medical care.
Patient Centered Approach

• Transition with dignity
• Significant other involvement
• Exercising choice
• Increased patient satisfaction
• Impact on QoL
• Assisting patient’s mental transition of care for life sustaining to hospice
Hospital discharge status of patients in the Acute Decompensated Heart Failure Registry (ADHERE) database

End-of-Life Care: Do I Want to Stop Life-Prolonging Treatment?

Your choices
- Stop treatment that prolongs your life. Instead, receive only treatment that focuses on your comfort and quality of life.
- Don’t stop treatment that prolongs your life.

Key points in making your decision
- If there is a good chance that your illness can be cured or controlled and you are willing to deal with the possible side effects of the treatment.
- A cure for your illness is not likely, and you want care that eases your symptoms until death occurs.
- You do not want treatments that, though they may prolong your life, may have side effects that greatly decrease the quality of your life, or may shorten your life.

Circle the answers that best apply to you.

| I have a terminal illness, and I want treatment that may cure or control my illness. | Yes | No | Unsure |
| A cure for my illness is not likely, and I want care to ease my symptoms until I die. | Yes | No | Unsure |
| Medical treatments may cure my illness and prolong my life. | Yes | No | Unsure |
| I have other health problems that impact whether I choose curative treatment or end-of-life palliative care. | Yes | No | Unsure |
| I want support services, such as hospice, that are common with end-of-life palliative care. | Yes | No | Unsure |
| Cost is not a factor for me. | Yes | No | Unsure |
Implications for Healthcare

• Patients and families who have not participated in timely goals of care discussions may have a less than optimum opportunity to have a death experience that could be shared in a way that is most meaningful them.

• We play a key role in helping members of the interdisciplinary care team better understand the barriers, challenges and needs related to the HF trajectory and end of life preparation, especially in African Americans.
Are Goals of Care Discussions Too Late?

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