Heart Failure: Prognosis, Disease Trajectory, and Device Discussions

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Disclosure

• No financial disclosures

Objectives

3 things I want you to take away from this session:

• Why illness trajectory is clinically useful in advanced heart failure
• Learn how to discuss illness trajectory in advance care planning (ACP)
• What good palliative care can do for heart failure
What do we know already about heart failure in advanced care planning (ACP)?

- Prognosis and timing is difficult to predict
- Patients want to know about their progress and plan for the future
- Doctors want to have this conversation with the patients but don’t do this early enough

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<table>
<thead>
<tr>
<th>Cancer Patient</th>
<th>Heart Failure Patient</th>
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<tbody>
<tr>
<td>• Clinical trial</td>
<td>• Advanced outpatient program</td>
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<tr>
<td>• Hyperthermic Intraperitoneal Chemotherapy (Hipec)</td>
<td>• Investigational drugs</td>
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<td>• Hospice</td>
<td>• BiV pacer</td>
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Which patient is at the end of his life? *

52 year old man with metastatic colon cancer s/p resection and 3 rounds of chemotherapy. He is now readmitted for decreased oral intake, weakness, lethargy. He has lost 20 pounds and spends 50% of his day in bed.

52 year old man with HTN, DM, CABG x2 and hypercholesteremia. His EF < 30% and he has a prolonged QT interval on his EKG. Readmit for increasing SOB due to worsening HF, no precipitating factors. He complains of decreased oral intake, weakness, lethargy. He has lost 20 pounds and spends 50% of his day in bed.

* NB: Advance Care Planning not just for patients at EOL

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Options

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Cancer Patient

- Clinical trial
- Hyperthermic Intraperitoneal Chemotherapy (Hipec)
- Hospice

Heart Failure Patient

- Advanced outpatient program
- Investigational drugs
- BiV pacer
- High Risk CV surgery
- Inotropes
- Mechanical Circulatory Support
- Transplant
- Hospice
Why is Advance Care Planning different for Heart Failure?

It's always too soon... until it's too late.

Heart Failure Disease Trajectory

- Excellent
- Initial
- Early
- Middle
- Late
- Transplant or VAD
- Sudden death event
- Death

Adapted from Goldin, 2005.
What to do at time of initial diagnosis

- Explain that heart failure is a chronic illness
  - This is a disease from which they may or may not recover
  - Many people can be asymptomatic for years
- Establish legal surrogate decision maker

“Who would you want speak for you if you were ever unable to speak for yourself?”
What does early phase look like?

- Heart failure exacerbation +/- recent hospitalization
- >3-6 months after initial diagnosis
- Already on optimal medical therapy for heart failure
- **START YOUR CONVERSATION DURING OR SHORTLY AFTER HOSPITALIZATION**

What to do during early phase

- **Establish illness understanding**
  - Introduce and explain illness trajectory concept
  - Unpredictable phase, but may be years
- **Understand and establish coping mechanisms**
  - How will the patient manage their illness?
- **Advance care planning**
  - **Who will be surrogate decision maker?**
  - What are the possible future therapy e.g. ICD, CRT, transplant or VAD, and what do these do?
I understand that you have been diagnosed with heart failure recently, and it seems things are under control now. While you may remain like this for years, you may have a few ups and downs. You can do a lot to manage your illness well. What do you think?

“If your heart failure worsens, you may come to learn about therapies like a pacemaker, or a defibrillator. You won’t be needing these for a while, but do you think you would want the therapy when the time comes?”

What you can say

- “I understand that you have been diagnosed with heart failure recently, and it seems things are under control now. While you may remain like this for years, you may have a few ups and downs. You can do a lot to manage your illness well. What do you think?”

- “If your heart failure worsens, you may come to learn about therapies like a pacemaker, or a defibrillator. You won’t be needing these for a while, but do you think you would want the therapy when the time comes?”

What does middle phase look like?

- Change in outcome predictors
  - NYHA class
  - Recurrent hospitalizations
  - Renal dysfunction
  - Lower systolic blood pressure

- Referral for Implantable cardioverter defibrillator (ICD) or Cardiac resynchronization therapy (CRT)

- START YOUR CONVERSATION IF YOU ARE DEALING WITH ANY OF THE ABOVE
What to do during middle phase

- Establish illness understanding
  - Review illness trajectory diagram
  - What is the patient’s understanding of their illness?
  - Recommendations about device and medical management, and what options are available

- Understand patient values
  - What things are important to the patient?

- Advance care planning
  - Review code status (likely full), but foreshadow a time when resuscitation doesn’t make sense

What you can say

- “What are you hoping for with regards to your heart failure? What helps you live well?”

- “What is most important to you if you got sicker? What worries do you have about your health?”

- “You’re not going to die anytime soon, but would you be able to tell me about how you would like to spend the end of your days?”

- “At what stage in your life would you not want to be brought back to life with CPR and defibrillator shocks?”
What does late phase look like?

- Inotrope dependence
- Declining functional status
- Recurrent/prolonged hospitalizations
- Even their dog knows they’re dying
- **START YOUR CONVERSATION IF YOU HAVEN’T ALREADY!**

What to do during late phase

- **Establish illness understanding**
  - Reassess patient’s prognostic awareness
  - If unrealistic, gently explain that they have moved into the last stage of illness
- **Establish patient values**
  - How do they want to spend the last few days? What is important to them now?
- **Advance care planning**
  - Recommend comfort-focused care, including hospice
  - Symptom management with or without medications

What to do during middle phase

- Don’t forget to turn off the ICD device (if applicable) when nearing end of life because **IT HURTS!**
- And no one likes to be shocked when they’re awake and conscious, and the families don’t want to see the ongoing shocks when the patient is dead
What you can say

“It is very difficult for me to tell you this, but I think you are on the last stage of your journey. I want to know what is important to you, and how you want to spend the time that you have left, so that we can make it happen for you.”

“We want to make sure that you are as comfortable as possible – no painful procedures, no unnecessary interventions. We want to keep you as pain-free as possible, and reduce your breathlessness, and there are some medications we can give you for these symptoms. Hospice places great emphasis on these values.”

ACC/AHA Practice Guidelines

Goal Setting in Patients with Advanced Illness

• Instead of focusing on treatments, focus on outcomes and overall goals
  • What is the desired outcome?
  • What is the “fate worse than death”?

• Some common goals
  • Be able to interact in a meaningful way
  • Be free of pain
  • Live as long as possible
Take home messages for heart failure

- Heart failure is a chronic disease that can be managed for months to years, but is often a terminal diagnosis.
- Prognosis is highly variable and uncertain, but illness trajectory is more predictable. You don't need to give a time frame for when they are going to die.
- Between chronic outpatient care, heart failure patients have many hospitalizations with huge rescue efforts.
- There are plenty of opportunities to initiate conversations so your patient can live and die well!

What can you do?

- Seize the opportunities to have a conversation with your patient, whichever stage of their diagnosis, it can be as short as two minutes.
- Create a culture among your colleagues so that initiating conversations becomes the norm.
- Reflect on your attitude – “what is stopping me from initiating these conversations?”
- Empower your patients to share their goals and priorities.

Video
What did the doctor do well?

- Explained what the patient can expect
- Asking for permission (shows respect to patient)
- Involving family members to be a part of decision making
- Slow explanation with pauses to allow information to sink in (a lot of information!), and normalizing this
- Acknowledging emotions (you seem confused…)
- Asking the patient to summarize
- Specific goals and the clarifying the role of the intervention