Heart Failure Throughout the Continuum of Care: Where does Palliative Care fit in?

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Learning Objectives

By the end of the session, participants will be able to:
• To understand the various symptoms in advanced heart failure and possible interventions.
• To recognize the challenges of having conversations about goals of care in advanced heart failure and have approaches to discussions.
• To discuss the unique challenges faced by patients living with advanced heart failure both at home and in long term care.
Impact of Heart Failure

- 6+ million Americans
- Nearly 700,000 new cases per year
- More than 280,000 patients die of heart failure in the US each year
  - 2nd highest mortality at one year with optimal medical management

Impact of Heart Failure

- Nearly 250,000 patients are considered at high risk for repeated hospitalizations
  - More than 1 million hospitalized for worsening heart failure at a cost of nearly $35 billion
  - 20% of hospitalizations are persons over 65
- Over 100,000 patients have advanced end-stage heart failure characterized by:
  - frequent hospitalizations
  - reduced quality of life
  - a complex therapeutic regimen, and a high mortality rate

SYMPTOMS IN HEART FAILURE AND INTERVENTIONS
HFSA 2010 Definition of HF

- Syndrome caused by cardiac dysfunction, due to myocardial dysfunction or loss
  - neurohormonal and circulatory abnormalities
  - pulmonary and systemic venous congestion and/or inadequate peripheral delivery
- Characteristic symptoms
- Usually progressive
  - can be stabilized and dysfunction and remodeling may improve

Types of Heart Failure

- Systolic heart failure
- Diastolic heart failure
- Right sided heart failure
- Left sided heart failure

Three common HF presentations

- Decreased effort/exercise tolerance
  - Dyspnea, fatigue
  - May be mistakenly attributed to aging, deconditioning, or other medical disorders
- Fluid retention
  - Leg, abdominal swelling reason for seeking attention
  - Other symptoms may be subtle
- Incidental finding
  - No symptoms
  - Symptoms of another cardiac or noncardiac disorder
  - Abnormal test
Neurohormonal Activation

Symptoms of Worsening Heart Failure

- Volume Overload
  - Shortness of breath
  - Orthopnea, PND
  - Swelling and abdominal bloating
  - Lightheadedness
  - Palpitation

- Low Cardiac Output
  - Fatigue
  - Anxiety/agitation
  - Confusion
  - GI discomfort
  - Lightheadedness
  - General discomfort

Markers of Poor Prognosis

Table 17: Conditions associated with a poor prognosis in heart failure

<table>
<thead>
<tr>
<th>Condition</th>
<th>Hemodynamic</th>
<th>Biochemical</th>
<th>Functional</th>
<th>Laboratory</th>
<th>Imaging</th>
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</thead>
<tbody>
<tr>
<td>Anemia</td>
<td>Increased</td>
<td>Increased</td>
<td>Reduced</td>
<td>Increased</td>
<td>Normal</td>
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<tr>
<td>Renal failure</td>
<td>Decreased</td>
<td>Decreased</td>
<td>Increased</td>
<td>Normal</td>
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<tr>
<td>Hypertrophy</td>
<td>Decreased</td>
<td>Increased</td>
<td>Normal</td>
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<tr>
<td>Low cardiac output</td>
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References:
AMDA Long Term Care Medicine - 2014
SYMPTOM MANAGEMENT STRATEGIES

Symptom Management of End Stage HF

Dyspnea: Etiology

- Multifactorial
- Related to respiratory changes
  - Changes in lung stiffness, dead space, VQ mismatch, increased work of breathing and impaired ventilation with diaphragmatic splinting (HSM, ascites)
- Central chemoreceptors responding to changes in CO2 and pH
- Muscular due to skeletal muscle wasting
- Myocardial (ischemia)
- Psychological and social
  - Anxiety and fear
  - Compliance and adherence issues

Symptom Management of End Stage HF

Dyspnea: Treatment

- Loop diuretics
- Intravenous diuretics
- Opioids – reduce hypoxic ventilatory drive – may unload volume by acting on opioid receptors in the lung
- Oxygen supplementation in the absence of hypoxemia is not effective, although some patients do report symptomatic benefit therefore, only for patient comfort.
- Lower extremity strengthening
Symptom Management of End Stage HF

Fatigue

- Common secondary to worsening HF, deconditioning, depression/anxiety, and elevated neurohormones
- Management
  - Energy conserving strategies (planning your day to maximize rest and periods of activity/exertion)
  - Screen for underlying psychiatric issues
  - Treat anemia
  - Use of CPAP for those with sleep apnea; may trial oxygen as well
  - Exercise (LE strengthening)
  - Psychostimulants (methylphenidate 5-10mg po BID)

Symptom Management in End Stage HF

Pain

- Occurs in 40-75% of HF patients
- PAIN-HF trial recently released which characterizes the experience of pain in advanced heart failure patients.
  - Severe to very severe pain 1/3 of the time
  - Predictors of pain included DJD, dyspnea and angina.
- Patients without ischemic heart disease experience “angina/chest pain”
- Location is not specific and etiology not known

Symptom Management in End Stage HF: Pain

- Local treatment with heat/cold therapy, physical therapy, topical salicylates or capsaicin or joint infections if indicated
- Low-dose opioids
- Avoid NSAIDs
- Pain associated with ischemic heart disease is managed with antianginals, EECP, TMR and there are some interventional pain management options (thoracic spinal cord stimulator, thoracic epidural analgesia)
Symptom Management in End Stage HF: Anorexia/cachexia

- Treatment of volume status and HF medical management
- Complex etiology to cardiac cachexia without a simple answer.
- Encourage small, frequent meals as tolerated, especially for patients with mechanical circulatory support.
- Sudden changes in appetite may be an early sign of impending cardiogenic shock or disease progression.

Symptom Management in End Stage HF: Spiritual and Psychological

- Patients often have difficult social situations and some of these may have limited eligibility for VAD and transplant.
- Treatment for depression/anxiety
- Refer to chaplain services when there may be evidence of existential suffering or significant grief
- Sources of grief:
  - Loss of independence
  - Loss of life
  - Loss of social status: unable to work, participate in church or community
  - Loss of role within the family

Symptom Management in End Stage HF: Depression

- 1 in 5 patients with HF meets criteria for a major depressive disorder and a greater number report depressive symptoms.
- Depressive symptoms are highly correlated with decreased QOL, increased pain and worsened clinical outcomes
- Only clinical trial is SADHART-CHF (sertraline v. placebo for 12 weeks): too short and lower dosing than usual
- SSRIs are considered standard of care for depression in heart failure
- Nonpharmacologic: exercise, supportive counseling, assess sleep disordered breathing.

LeMond, L et al. Progress in Cardiovascular Diseases, 2011.
DO HEART FAILURE MEDS PALLIATE?

ACE Inhibitors

• Improve dyspnea, fatigue, orthopnea and edema patients with NYHA Class II-III HF; J Am Coll Cardiol 1983
• Improve duration of exercise & 6 min walk distance in LVSD; Heart 2002
• Improve 6 min walk distance and NYHA class in HFnEF; Eur Heart J. 2008
• (perindopril improved 6 min walk distance in elderly without HF)
• Prolong life and reduce hospitalization in HFrEF

Angiotensin Receptor Blockers (ARBs)

• Valsartan improved composite fatigue and dyspnea scores versus placebo in patients with poor left ventricular function; Eur J Heart Fail. 2006

• Prolong life and reduce hospitalization in HFrEF; reduce hospitalization in HFpEF
Beta Blockers

- Carvedilol, Metoprolol Succinate & Bisoprolol:

- Outcomes:
  - prolong life
  - reduce hospitalization and
  - improve function (after 2-6 months) in HFrEF

Carvedilol & Symptoms

Chronic Inotrope Infusion Associated with High Mortality

- OPTIME-CHF and PROMISE
- Randomized, double blinded
- 1000 patients/ea randomized to milrinone or placebo
- High rates of hypotension, arrhythmia, syncope
- 53% increase in mortality
  - Pts not "wet and cold"
  - Inotropic therapy was not considered essential for management
Continuous Outpatient Support with Inotropes: Palliation

- 36 patients
  - Inotrope-dependent
  - Refused/ineligible for transplant
- Rehospitalizations infrequent
- Infection/sepsis common
- Survival 3.4 months
  - Most died at home

![Table 1: COSE Outcomes](source)

Recent Patient Experience

- T.S. is a 65 y/o gentleman. Married for 43 years with 2 sons and 6 grandchildren. Two sisters involved in his care.
- Stage D, NYHA Class 3B to 4 HF from ischemic cardiomyopathy
- Stage IV CKD (CAD, DM, HTN) but rapidly nearing dialysis with management of his volume
- Admitted with chest pain and acute decompensated HF. Refused hemodialysis and cardiac cath. Had a mild heart attack when dobutamine was tried.
- Palliative care consulted for GOC

Recent Patient Experience

- I came on service: trying to diurese, kidneys failing, on CPAP but unable to get documentation needed to continue as an outpt but getting symptomatic benefit. Full Code.
- GOC: wants to get home, wants to live longer ("I think I have 20 years left), wants to spend time with grandchildren.
- Further conversations: consideration for HD (less overwhelmed at this point). Wife very concerned about history of noncompliance. Discussed hospice as an option as well.
### Recent Patient Experience

- After multiple conversations about realistic hope, readdressing goals of care and what is achievable, the challenges he will face with and without hemodialysis, the stress his wife and family are under, his decisions:
  - Declined hemodialysis.
  - Changed code status to DNR (initial response was to give it a shot for awhile but he didn’t want to be on machines any further).
  - High dose diuretics for comfort with option for IV diuretics at home.
  - Enrollment with local hospice.
  - Able to provide CPAP at home.
  - All family in agreement although grieving.
  - Started a memory journal.

### HAVING THE CONVERSATION: WHAT MAKES IT SO DIFFICULT?

### Barriers to Effective Palliative Care/Supportive Care in Heart Failure

- Providers not sure who is responsible for the discussion.
- Poor community awareness of HF and sequelae
- Lack of integrated care systems
- Difficulties in timing and having the resources to address death and dying issues
- Limited evidence for HF symptom management at end of life
- Struggle to reconcile the goals of palliative care within the dynamic and highly technological therapeutic context of heart failure
<table>
<thead>
<tr>
<th>What makes the Conversations Difficult for Providers?</th>
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<tbody>
<tr>
<td>• Prognostication is not an exact science</td>
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<tr>
<td>• Fear of taking away hope and the perception that they are “giving up” on the patient</td>
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<td>• Time consuming</td>
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<td>• Poor training for having these types of discussions</td>
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<tr>
<td>• Personal values, beliefs and attitudes</td>
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<tr>
<td>• Fear of that death is the equivalent of failure or inadequacy</td>
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<th>Effective planning demands having “difficult” conversations</th>
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<table>
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<tr>
<th>What makes the Conversations Difficult for Patients?</th>
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<td>• May indicate a significant change in illness trajectory</td>
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<tr>
<td>• Everyone responds to poor prognosis differently (related to personality, social situation, past experience with illness, current disease burden)</td>
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<tr>
<td>• May actually be a relief for some patients to actually discuss it but they haven’t known how to start the conversation.</td>
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<tr>
<td>• Patients often feel that they are failing their care teams by changing their goals</td>
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THE CHALLENGES OF HEART FAILURE IN LONG TERM CARE/SNF SETTINGS

The Trajectory of Heart Failure

Prognostic Considerations

- Challenges in discussion due to the pattern of decompensations and plateaus.
- Those who develop a new disability in an ADL has only a 30% chance of getting back to prior level of function.
- Features of those who transition home without disability:
  - Intact gross motor coordination and manual dexterity
  - Absence of cognitive impairments
  - Absence of significant weight loss

Goodlin, S, JACC, 2007
Consideration of Different Populations

- Patients who come to skilled facility as a rehabilitation patient bound for home
- Patients with uncertain prognosis (multiple comorbidities, frailty, recent complications while in hospital)
- Patients in long term care with issues of frailty and dependency who are in a care setting for life.

A Basic Approach to HF in LTC

- At admission:
  - Rehabilitation potential
  - Overall health status
  - Patient and family goals of care and advanced directives
  - Consider if the patient is high or low risk for acute decompensations
  - Obtain a baseline assessment and create a plan of care

Components of Baseline Assessment

- Understand etiology of HF and assessment of left ventricular ejection fraction (LVEF)
- Determine weight goals and “call for” parameters to allow early intervention
- Obtain baseline vital signs including orthostatics
- Review current heart failure meds
- Identify meds to avoid (ie: NSAIDS)
- Identify need for fluid and sodium restriction (is this possible for your facility?)
- Create and document plan of education for patient and family.
- Identify early how decompensations will be handled.
Acute Decompensated Heart Failure

• Early recognition is key.
• Refer to patient’s acute management plan
  – Who to contact
  – Diuretic escalation plan
  – Triggers for hospitalization
  – Review of goals of care
    • Consider where they are of the spectrum of disease in terms of rehab potential and comorbidities.
  – Every decompensation should trigger a reassessment of GOC

Challenges in Assessing HF in the LTC Patient

• Cognitive impairment
• Sedentary lifestyle
• Comorbidities that can have similar symptoms
• Weight gain is often the goal for the LTC patient
• Variations in staffing patterns and skill levels with regard to assess fluid status.

Case Study

• SM: 69 y/o woman with CAD, DM, chronic systolic heart (LVEF 18%), primary prevention ICD and chronic kidney disease.
  – Initial presentation: living at home, 8 hospitalizations in 10 months including 2 ICU stays and one intubation. Two hospitalizations were for diverticulitis but complicated by ADHF. Increased debilitation. Loss of muscle mass although obese. Fatigue, DOE, orthopnea, edema. Limited HF meds.
  – Social: living alone, daughter and sister nearby; struggling to manage home, meds and meal prep.
  – Patient goal: wants to live but is afraid of mechanical support and transplant.
  – What could you do next?
Case Study

- I readjusted meds, counseled extensively on sodium and fluid restriction, discussed ventricular assist devices and transplant but also reviewed obstacles to this.
- Education material provided with a 4 week follow up.
- HF nurse practitioner did a reach out in two weeks and:
  - Increased dyspnea
  - 15 lb weight gain
  - Anorexia with significant edema
  - Thus doubled diuretics

Case Study

- And...admitted for the 9th time with acute decompensated heart failure, acute kidney injury, deconditioning and depression.
- Intubated for 5 days but recovered and extubated.
- Now, recommended to go to a skilled nursing facility for rehab and plan for follow up at my advanced HF/transplant clinic in 6 days.
- Readdressed goals of care and thoughts on VAD/transplant. Family is more involved and advocating.

Consider if She Came To You

- What is her rehab potential?
- Comorbidities/health status?
- Is she high risk or low risk for readmission?
- What do you know about her meds?
- What can we do about her risk of ADHF?
- What are her GOC?
- What are her triggers?
- How will you manage her decompensations?
Case Study

- Remained in facility for 60 days with remarkable stabilization of symptoms and no further hospitalizations.
- Tolerated med uptitrations
- After mild weight gain due to high salt food from home needed more diuretics. DOE and weight improved.
- Follow up clinic visit she wanted to consider VAD but not transplant.
- Evaluation started for advanced cardiac therapies including palliative care consultation.

Consider a VAD

Long-term Survival for Destination Therapy Ventricular Assist Devices

Case Study

- Approved for destination therapy VAD
- Discharged from SNF after 2 months
- Understood meds and diet management
- Able to track own weight
- Admitted to DT VAD but discharged without device because of marked clinical improvement and after GOC conversations.

Hope

- Hope is both a noun and a verb
  “Hope is the possibility of the not yet”
- Hope is a feeling, a desire, an expectation of something, a certain thing to happen. Typically is a hope for something GOOD.
- It is often used in dire situations or difficult times. “Our only hope is for the rain to come.” “Now all we can do is hope.”
  As a verb, it conveys concern, support
Hope in HF Patients

• Reality is very vague
• They have “beaten the odds” many times
• Heart Failure: they’ve accommodated to this word
• Death has been a constant reality

• Hope is not wishing; not magical thinking
  “I wish I could get all better.”

There is Always Hope

• That is because hope is not static or unchanging
• It is always in process, evolving
• It is our challenge to redefine hope.

  “I hope your meds help your pain.”
  “I hope you get good time with your family.”

Miracles: a gift, not something we can make happen

Closing Thoughts

• Heart failure is pervasive, fraught with many forms of suffering and impacted by many things.
• HF meds offer palliation and there are strategies to manage the multitude of symptoms
• These conversations can be hard for patients, families and providers. The key is normalizing discussions about goals.
• We can always offer hope-realistic and tempered with understanding of the patient and the disease.
• Throughout the continuum of HF care, in all settings, success is driven by planning ahead.