300- Meet the Expert Breakfast Session: Heart Failure Throughout the Continuum of Care: Where Does Palliative Care Fit In?

Saturday, March 19

6:00 AM-7:45 AM

Session Description

In this session, KellyAnn Light-McGroary, MD, will discuss the impact of heart failure from a population and an individual perspective as well as explore the ways in which palliative care and hospice can be integrated into a chronic disease model such as heart failure. She will review the common symptomatic challenges often faced by advanced heart failure patients and how a variety of pharmaceutical and non-pharmaceutical interventions can be employed to palliate them. Finally, Dr. Light-McGroary will explore the challenges that exist in having conversations about goals of care in patients with advanced heart failure and what strategies can be tried to deal with these issues.

Learning Objectives

- Compare and contrast palliative care and hospice and how each can be useful in the heart failure patient.
- Discuss the various symptom manifestations of advanced heart failure and the possible “palliative” interventions.
- Identify the challenges of having conversations about goals of care in advanced heart failure.

Presenter(s): KellyAnn Light-McGroary, MD

Presenter(s) Disclosures: KellyAnn Light-McGroary, MD: Bayer Pharmaceuticals: local principal investigator for sever multi-center clinical trials
Heart Failure Throughout the Continuum of Care: Where does Palliative Care fit in?

KellyAnn Light-McGroary, MD
Cardiomyopathy Program & Palliative Medicine Program
University of Iowa Hospitals and Clinics

Learning Objectives

By the end of the session, participants will be able to:

- Recognize the various symptoms in advanced heart failure and possible interventions.
- Explain the challenges of having conversations about goals of care in advanced heart failure and have approaches to discussions.
- Discuss the unique challenges faced by patients living with advanced heart failure and advanced cardiac therapies.

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

Speaker Disclosures

Dr. Light-McGroary - Bayer Pharmaceuticals: Local principal investigator for severe multi-center clinical trials.

Impact of Heart Failure

- Nearly 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

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

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

Types of Heart Failure

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

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
**SYMPTOM MANAGEMENT STRATEGIES**

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**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

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

### 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
  - Inotropic-dependent
  - Refused/eligible for transplant
  - Rehospitalizations infrequent
  - Infection/sepsis common
  - Survival 3.4 months
  - Most died at home

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### 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 outpatient 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 overwhelming at this point). Wife very concerned about history of noncompliance. Discussed hospice as an option as well.
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

What makes the conversations difficult for providers?

- Prognostication is not an exact science
- Fear of taking away hope and the perception that they are “giving up” on the patient
- Time consuming
- Poor training for having these types of discussions
- Personal values, beliefs and attitudes
- Fear of that death is the equivalent of failure or inadequacy

What makes the conversations difficult for patients?

- May indicate a significant change in illness trajectory
- Everyone responds to poor prognosis differently (related to personality, social situation, past experience with illness, current disease burden)
- May actually be a relief for some patients to actually discuss it but they haven’t known how to start the conversation.
- Patients often feel that they are failing their care teams by changing their goals

Effective planning demands having “difficult” conversations
**LIVING WITH ADVANCED CARDIAC THERAPIES: UNIQUE AND UNDER-RECOGNIZED SUFFERING**

**How do transplant patients die?**

- Acute Rejection
- CAV
- Graft Failure
- Severe Failure
- Infection (Non-CMV)
- Malnutrition

**Long-term survival for destination therapy ventricular assist devices**

**QOL and Care Trajectory after DT**

- Grief of loss of roles
  - Family
  - Community
  - Workplace
- Grief of loss of opportunities
  - Decreased longevity
  - Impact on being there for “milestones” for family
  - Having to imagine a different life, even when they reach a “successful” outcome like transplant

**ADULT HEART TRANSPLANTS**

Kaplan-Meier Survival by Era

(Transplants: January 1982 - June 2010)

**How do these patients suffer?**

- Grief of loss of roles
- Family
- Community
- Workplace
- Grief of loss of opportunities
- Decreased longevity
- Impact on being there for “milestones” for family
- Having to imagine a different life, even when they reach a “successful” outcome like transplant
How do these patients suffer?

- Impact of being a transplant recipient/candidate
  - Gaining life at the expense of someone else’s loss of life
  - Meeting donor families
  - Fear of not getting a donor
  - Fear of losing a graft
  - Mismatch between the expectations after transplant and what actually occurs.

Case Study

- DS: 64 y/o man with CAD
  - Post pericardiotomy shock requiring perioperative centrimags (3/28/13), post op renal failure on HD
  - Total Artificial Heart placed (4/9/13)
  - Persistent renal failure on CVVH (needs kidney txplt)
  - Multiple GI bleeds for ischemic bowel (2 operations)
  - Recurrent sepsis and 5 intubations
  - Disseminated cryptococcal infection on amphotericin
  - Symptoms: anxiety, pain (abdominal, canula), dyspnea, cachexia/malnutrition, severe deconditioning

  - Patient and family goal: TRANSPLANT

Case Study

- Palliative Care Involvement
  - First consult: prior to TAH for ACT preparedness planning and goals of care
  - Ongoing psychosocial support until end of May
  - Re-consult: early August to address goals of care, futility and symptom management
  - Facilitated multidisciplinary care conference including patient and family
  - Present at transplant selection meeting
  - Provided ongoing legacy building and dignity therapy
  - Assist medical staff with grief support and ethical concerns

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
Honoring Your Wishes

- Use the hypothetical: What if....
- Help define values
- Help consider extremes/limits
- Make sure a loved one is present UNLESS they interfere with process

Closing Thoughts

- Heart failure is pervasive, fraught with many forms of suffering.
- 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.