Palliative Care in Advanced Heart Disease
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Objectives

1. Be able to list 2 reasons for a palliative care consult in the heart failure population

2. Be able to manage 3 common symptoms in the heart failure population

3. Be able to approach difficult goals of care conversations with a structured approach
Janet M

- 55 yo female with ICM (EF 20%), s/p CABG, multiple PCIs, DM, HTN, CKD 3, morbid obesity, OSA, and recurrent hospitalizations for HF exacerbations.
- First Palliative Care encounter: 7/10/13; consulted for pain management during HF admission (PN pain and abdominal pain). She had been on hospice and was referred back there.
- My first encounter: 4/14/15.
  - Her definition of quality of life was related to being in relationship to her granddaughters: “when she was pregnant with her first child, she was homeless, living out of dumpsters, and built a life for herself and her children. She hopes to offer her grandchildren a better life than she had herself, and better than what she was able to offer her children.”
  - In the following year, she was seen 4 times (with 7 phone contacts) to manage her symptoms and was never admitted.
  - On 6/8/16, she was seen with complaints of chronic PN pain, depression, insomnia, and heart failure-related symptoms.
  - On 9/26/16, she was seen at the HF clinic and referred back to hospice care at home.
  - She remained at home with hospice support until 2/17 when she was admitted to the inpatient hospice center for management of dyspnea/ascites. She was stabilized and transferred to the “Hospice house.”
  - Sadly, her grandchildren and children did not visit her or engage in discussions/decisions about her care.

Keith F

- 68 yo male with NICM (hemochromatosis) s/p ICD, VAD x2 afib, CKD who was admitted with increasing LDH and concern for repeat VAD clot. He underwent his second VAD exchange on 2/3/17, with washout procedure due to pocket infection/sepsis.
- Wife had even more anxiety than him.
- We were asked to follow with anxiety/depression.
- He had expected situational anxiety/depression and was on melatonin 6 mg qhs.
- No other psychotropics.
- He responded quite well to “talk therapy.”
Primary Palliative Care vs Palliative Consultation

- Primary palliative care: palliative principles practiced by the primary or specialty services
  - Heart Failure services do well with this: they recognize the psychosocial elements of care that impact compliance
- Palliative Consultation indications
  - Uncontrolled symptom burden
    - This is very prevalent and often unrecognized
  - Intersections of decisions/GOC discussions
  - Poor Prognostic concerns:
    - More than two admissions for HF in previous year
    - Burden of co-morbidities (renal failure, anemia, Pulm. HTN, Na<132, etc)

Palliative Perceptions of HF team

- Overall perception: admiration
  - HF team works as a team
  - HF team incorporates psychosocial elements of care
  - HF team remains patient/family centered
- How does the HF team utilize Palliative Care?
  - Still a thinking of “there’s nothing else to do, we’ll call palliative”.
    - Symptom management is essential to quality of life which translates to “length of life”
    - Shift from “if/then” thinking to “both/and” thinking

Palliative Care and VAD patients

- Pre-VAD eligibility work up should include palliative care consultation
  - Our role is to assess symptom burden
  - We also address expectations in regards to quality of life
  - If patient able/willing, we discuss end of life decisions on the other side of the VAD: they will not die naturally and their family/loved ones will need to make difficult decisions. We open this ongoing dialogue.
- We do not assist them in a decision process about the VAD. We find that the HF team does a comprehensive, outstanding job at that.
Snapshot of Palliative at UVA

- 2/16/17
  - 29 patients on our consult service
  - 3 from HF service
  - 2 from TCV service
  - 6 from Gen med services
  - 5 from ICU services
  - 5 from Cancer care services
- Heart failure at UVA is steadily increasing
  - Volume of consults
  - Earlier consults
  - Reasons for consults

Disease Trajectories

- Sudden death
- Cancer
- Organ Failure
- Frailty


Disease Trajectories

- Organ System Failure Trajectory
  - Time frame – usually 2-5 years
  - (mostly heart and lung failure)
  - Death usually follows disease exacerbation
Prognosis

Important factors to consider
- Co-morbid illnesses
- Rate of decline
- Nutritional status
- Functional status
- Cognitive status
- Age and gender
- Number of hospitalizations in past year
- Will to live
- Other (psychosocial, emotional and spiritual)

Cardiovascular Disease

- NHPCO guidelines
  - NYHA Stage IV – symptoms at rest
  - maximally treated with meds
  - EF < 20% (helpful, not required)
  - supported by treatment resistant arrhythmias, history of cardiac arrest, unexplained syncope, cardiogenic brain embolism, HIV

  Less than 50% accuracy at predicting mortality
  Unpredictable disease trajectory with high risk of sudden death

Cardiovascular Disease

- Recent cardiac hospitalization (3 x 1 yr mortality)
- Elevated creatinine > 1.4
- SBP < 100 or tachycardia > 100 (2 x 1 yr mortality)
- LVEF < 40%
- Ventricular dysrhythmias
- Anemia
- Hyponatremia
- Cachexia
- Reduced functional state
- Co-morbid illnesses

Fast Fact Concept #143
Ballpark Mortality for HFrEF
Stevenson LW, Rose EA, Circulation 2003

<table>
<thead>
<tr>
<th>Populations</th>
<th>Estimated 50% mortality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute cardiogenic shock</td>
<td>Imminent</td>
</tr>
<tr>
<td>Chronic CHF into low output state with organ dysfunction</td>
<td>1 month, without reversible factors</td>
</tr>
<tr>
<td>CHF Class IV inotrope–dependent</td>
<td>3–6 mos</td>
</tr>
<tr>
<td>CHF IV ACE–intolerant due to symptomatic hypotension or progressive renal dysfx</td>
<td>About 6 mos</td>
</tr>
<tr>
<td>CHF IV on ACEI therapy plus other risk factors: cachexia, hyponatremia, progressive renal dysfx</td>
<td>76–12 mos</td>
</tr>
<tr>
<td>CHF IV on oral therapy</td>
<td>~12 mos</td>
</tr>
</tbody>
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Cardiovascular Disease

- Cachexia
- Depression
- Multiple admissions
- Co–morbidities – DM, PVD, renal, dementia
- Age > 70
- Poor functional status
- HR > 100, Cr >2, inc sustained BNP
- LV volume > 85 mm (20% 2 year survival)

Palliation in heart failure, Davis, AJHPM 2005: 22, 211

Approximate Prognosis of 6–12 mos or less

- Frailty (walking speed 5m/6sec)
- >3 ADL deficits or decline in 1 ADL/past year
- HF hospitalizations: 4 in<65, 3 in >85
- Cancer
- COPD, Dementia, CKD
- BNP >500 compensated pts or >1000 decompensated patients
- Na < 132
- Cachexia (BMI <22.5 w/ 5% wt loss in 6 mos)
CHF – Prediction Models

- CVM-HF PREDICTOR
  - *Am J Cardiol* 2006;98:1076–1082
  - [http://www.ccort.ca/CHFriskmodel.asp](http://www.ccort.ca/CHFriskmodel.asp)
- SEATTLE HEART STUDY
  - *Circulation* 2006;113:1424–33. Levy et al. The Seattle Heart Failure Model: Prediction of Survival in Heart Failure

Biomarkers in Heart Disease

- Troponin – myocardial cell damage
- BNP – LV dysfunction
- Cystatin C – renal function
- CRP – inflammation

Increased risk of death when all four elevated

*NEJM* – 5/2008 Zethelius

Case Series

- Retrospective study
- Quantitative and qualitative analyses
- Designed to look at characteristics of patients referred for palliative consults and the symptom burden and care concerns evaluated/treated
- N=50 patients with 228 visits over 3 ½ years
Profile of patients seen

- 58% had NYHA Class III or IV heart failure
- 14% of patients died within a year of their first palliative care visit
- Referral triggers:
  - Stage C or D heart failure (symptomatic heart failure)
  - Declining functional status (NYHA Class III IV)
  - "You’re working, I wouldn’t be surprised if you died in the next year"
  - Loss of appetite, weight loss, physical wasting
  - 2 or more hospitalizations for heart failure exacerbations in past year
  - Patient is refusing medical/therapeutic treatments

Palliative Consult Triggers at Dana–Farber Heart Failure (ACTIVE) clinic

- Estimated prognosis of <6 mos
- Refractory symptoms despite max medical treatment
- Patient/family goals not aligned with disease severity
- 3 hospital admits or outpatient diuretic infusions in preceding year
- Home inotropic therapy without definitive advanced therapy options

Symptom management of Patients with Advanced Heart Failure

- Most commonly encountered symptoms
  - Dyspnea
  - Fatigue
  - Depression
  - Anxiety
  - Sleep disorders
  - Constipation
  - Nausea
  - Pain
  - Spiritual: Hope
Symptom burden

- Fatigue 62%
- Depression 50%
- Pain 47%
- Dyspnea 46%
- Sleep Disturbance 44%
- Anxiety 33%

***Medications were prescribed less commonly for fatigue, breathlessness, and sleep disturbance compared with depression, anxiety and pain.

Patient Concerns

- Symptom management
- Advanced Care Planning
  - Addressed in 33% of patients (one visit)
  - Addressed in 65% of patients (>one visit)
- Code status
- Care coordination in 58% of visits
  - Most common referrals to social work (26%), rehab/PT (20%)

Integration of UVA Palliative HF Services

- Consideration of naming our service in the heart failure clinic as “supportive care”
- Confirms our decision to hire an MSW, not an RN in the HF clinic
- Educational initiatives on treating depression, anxiety and fatigue
- Continued need for linking our care with the inpatient/outpatient/H2H services
Opportunities
- Improve symptom control
- Improve patient understanding of their disease trajectory and prognosis
- Reduce ineffective and burdensome medical interventions at the end of life
- Improve timely hospice referrals
- Improve hospice care for end of life care of heart failure patients

Short's best ways to fail at a Goals of Care Family Conference
1. Expect to have all the answers completed in one family meeting.
2. Expect everyone to be happy with the outcomes.
3. Hold the family meeting without all the important players.
4. Use a family member as your interpreter.
5. Go in with an agenda.
6. Go in with someone else's agenda.
7. Start the discussion with a discussion about code status.

The Language of a Family Meeting
- This is not a meeting spoken in medical language
- This is not a meeting explaining medical language
- This is a meeting intended to help a family love and care for their loved ones
- This is about speaking the family's language of caring, of loving.
What is “Quality of Life”?

Family Meeting/Goals of Care

- A family meeting/goals of care discussion is like any other medical intervention
- Done well: it can offer healing and hope
- Done poorly: it can cause harm and unintended injury to the patient and family
  - Misunderstanding of disease or prognosis
  - Misunderstanding of goals of treatment
  - Lack of involvement of patient in treatment planning

Does receiving unfavorable medical information cause psychological harm?

- The answer is NO!! 1,2
  - Patients want accurate and complete information to inform important quality of life decisions
  - Those who find information too threatening or overwhelming may deny, minimize, or avoid information while still participating in treatment

What about Hope?

- Do you take away hope when you share bad news?
- What is hope?
- How can you promote hope in the setting of a poor prognosis?

Structure of a Goals of Care Conversation

- Beginning (WHO): Focus on the person
- Middle (What): Focus on the current status
- End (Where): Focus on care plan

The Beginning: WHO

- The "time out" before entering the room: “Not my agenda, but your agenda”
- Setting up the meeting to be successful: no interruptions, everyone seated, everyone introduced, setting the agenda, previous discussions, decision making preferences
- Starting with the focus being on the person, not the patient: "I've spent the last 30 minutes reviewing all of your labs, scans, consult notes, etc... I know a lot about your medical condition, but I'd like to know about you, the person... as that is what is most important to us in treating you... can you tell me a little about yourself? What is important to you?"
The Middle: Closing the gap

What

- Start with an open ended question: “Can you tell me what your understanding of your condition is at this point? What have the doctors explained to you?”
  - The more that the patient/family talk (and the less the practitioner talks), the better the outcome of the meeting as perceived by the patient/family

- Clarify any gap of understanding between what the patient shares and what you know to be a realistic summary of their condition

The End: Recommendation

WHERE

- Always ask permission before making a recommendation
- Go back to the initial description of the person and what is important to them, and merge this with what you believe to be the most likely outcome/prognostic outlook and base your recommendation on these
- Give them time to reflect and respond to this and then decide together, a clear plan of care
- Summarize and close
Constipation in HF patients

- Causes of constipation
  - Gut motility limited by low CO
  - Bowel edema
  - Diuretics produce “dehydrated stool”
  - Limited overall mobility
  - Side effects of HF medications

- Consequences of Constipation
  - Nausea, abdominal pain, delirium
  - Vasovagal bradycardia, worsening dyspnea
  - Diminished quality of life

Constipation in HF Patients

- Treatment of Constipation
  - Use both a stimulant and stool softener
    - Senna S
  - Avoid fiber due to fluid restrictions
  - Needs to be addressed in an ongoing fashion

Nausea In HF Patients

- Causes of nausea
  - Mesenteric ischemia
  - Bowel edema
  - Gut dysmotility
  - Angina equivalent
  - Symptom of HF exacerbation

- Consequences of nausea
  - Anorexia, emesis causing aspiration
  - Diminished quality of life
Nausea in HF Patients

- Treatment of Nausea
  - Challenges with treatment choices due to QT prolongation
  - Consider: metoclopramide, haloperidol, ondansetron, Phenergan, Compazine

Pain in HF Patients

- Prevalence of Pain in HF patients
  - Occurs in 40–75% of HF patients
  - Severe to very severe 1/3rd of time
  - Predictors of pain: DJD, dyspnea, angina
  - Ischemic heart disease patients have “angina/chest pain”
  - Location not specific and etiology not known

Pain in HF Patients

- Local treatment for localized pain: compresses, topical agents, PT
- Low dose opioids if pain is compromising function/QoL
- Angina/chest pain is managed by antianginals
- Avoid NSAIDS/may use non-acetylated oral salicylates
Fatigue in HF Patients

- Prevalence
  - Very common due to worsening HF, deconditioning, depression/anxiety, elevated neurohormones

- Treatment of Fatigue
  - Look for and treat sleep disorders
  - Energy conservation strategies
  - Depression/anxiety screening and treatment
  - Treat anemia
  - Nocturnal or continuous oxygen
  - LE strengthening

Depression in HF Patients

- Prevalence
  - Very common

- Treatment of depression
  - SSRI's probably drugs of choice
  - Psychostimulants can be used safely (Ritalin 5mg bid)
  - Exercise is very helpful
  - Supportive counseling

Anxiety in HF Patients

- Treatment
  - No data in this population on how to treat
  - Evaluate for sleep disorders
  - Optimize management of dyspnea
  - Supportive care: ‘what is the meaning of the anxiety’
  - Benzos can be helpful, but use cautiously
Spiritual suffering in HF Patients

- Evolution of the concept of Hope
  - Hope for a cure gives way to hope for prolonging life which gives way to hope for comfort
- Grief/loss
- Existential questions surface
  - Did my life have purpose?
  - Issues of forgiveness
  - Life after life

Dyspnea

- “a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity” (American Thoracic Society)
- “An uncomfortable awareness of breathing” (Wasserman 1988)

Dyspnea (cont.)

- Dyspnea is subjective and has nothing to do with oxygen saturations. It is a symptom, not a sign.
- Dyspnea can have physical, psychological, social, and spiritual roots contributing to the etiology... similar to the concept of “total pain”.


Key to good symptom management: intervene early!!

Non-pharmacologic Treatment

- Re-position patient
  - Small pillow in lumbar area
  - Optimize the distance between groin to chin
  - Leaning forward sitting with arms propped
  - Positional changes to optimize drainage or to place “non-functional” areas in dependent position

Non-pharm treatments (cont.)

- Position of a fan to blow air across the face: this stimulates the V2 cranial nerve that does reduce a sense of dyspnea
- Supplemental oxygen regardless of saturations: blowing air or oxygen helps via V2 trigeminal nerve (Liss and Grant, 1988, Schartstein et al)
Pharmacological Treatment

- Opioids, Opioids, Opioids
  - Mechanism is not well understood: probably a central mechanism that blocks the perception of dyspnea
  - Safety has been consistently demonstrated: do not depress respiratory drive when used appropriately!!

- Route of use: IV, SQ, PO, (pill, liquid)
  - Nebulized opioids have not been proven to be more beneficial than placebo
  - Morphine is usual first choice unless renal function is impaired
  - All opioids are effective except Methadone
  - Strong data to support short term benefits; few data to support long term benefits

- Anxiolytics
  - Benzodiazepines can be helpful in alleviating dyspnea when there is a coexistent anxiety
  - There is no evidence to support the routine use of benzodiazepines in the management of dyspnea (Fabrio et al 2006)
  - Always use opioids first, even if anxiety seems significant
  - Buspirone (Buspar) has minimal benefit
Important elements of care as rated by patients, family, physicians, other caregivers

- Pain and symptom management
- Preparation for death
- Achieving a sense of completion
- Decisions about treatment preferences
- Being treated as a "whole person"