End Stage Heart Failure: Is there a role for Palliative Care?

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“It is easier to die of Cancer than Heart or Renal Failure.”

- John Hinton, MD, 1963
Objectives

- To define palliative care
- To define CHF (various stages, disease trajectory)
- To gain understanding of what a terminal CHF patient experiences towards the end of life
- To understand the barriers to palliative care in this population
- To become familiar with palliative treatment strategies employed in the symptomatic end-stage CHF patient
Palliative Care

- Provides care in the relief of pain and other distressing symptoms
- Affirms life
- Regards dying as a normal process
- Intends neither to hasten nor postpone death and offers a support system to patients (and caregivers) to help patients live as actively as possible until death
Heart Failure

- The inability of the heart to meet the metabolic demands of the body
- NYHA Classifications 1-4
<table>
<thead>
<tr>
<th>Class</th>
<th>Description</th>
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<tbody>
<tr>
<td>Class I</td>
<td>No limitations. Ordinary physical activity does not cause undue fatigue, dyspnoea or palpitation (asymptomatic left ventricular dysfunction)</td>
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<tr>
<td>Class II</td>
<td>Slight limitation of physical activity. Such patients are comfortable at rest. Ordinary physical activity results in fatigue, palpitation, dyspnoea or angina pectoris (symptomatically ‘mild’ heart failure)</td>
</tr>
<tr>
<td>Class III</td>
<td>Marked limitation of physical activity. Although patients are comfortable at rest, less than ordinary physical activity will lead to symptoms (symptomatically ‘moderate’ heart failure)</td>
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<tr>
<td>Class IV</td>
<td>Inability to carry out any physical activity without discomfort. Symptoms of congestive cardiac failure are present even at rest. With any physical activity increased discomfort is experienced (symptomatically ‘severe’ heart failure)</td>
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<table>
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<tr>
<th>Causes of heart failure</th>
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<tbody>
<tr>
<td>Ischaemic heart disease</td>
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<tr>
<td>Hypertension</td>
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<tr>
<td>Alcohol</td>
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<tr>
<td>Valvular disease</td>
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<tr>
<td>Viral myocarditis</td>
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<tr>
<td>Thyroid disease</td>
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Impact of CHF

• 5 million in US with Congestive Heart Failure
  • Approximately 550,000 new cases annually
• The total annual cost of caring for CHF in the United States is more than $30 billion, with 60 percent associated with hospitalization
• The costs of CHF hospitalizations typically exceed reimbursement, as the expenses associated with long length of stay quickly overwhelm the $6,000 average reimbursement provided by Medicare
• Hospice/Palliative Care services decrease these costs drastically
Natural History

- Grade 3 and 4 – median survival 1 year
- Grade 1 and 2 – 5 years
- UK studies: 5-year mortality rate 75% after 1st hospital admission
Incidence of and Number of Deaths Due to Heart Failure Compared With Other Common Causes of Death in the United States

<table>
<thead>
<tr>
<th>Cause of Death</th>
<th>Incidence</th>
<th>Deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heart failure</td>
<td>≈500,000</td>
<td>284,365</td>
</tr>
<tr>
<td>Lung cancer</td>
<td>196,252</td>
<td>158,006</td>
</tr>
<tr>
<td>Breast cancer</td>
<td>188,587</td>
<td>41,316</td>
</tr>
<tr>
<td>Prostate cancer</td>
<td>189,075</td>
<td>29,002</td>
</tr>
<tr>
<td>HIV/AIDS</td>
<td>37,726</td>
<td>16,395</td>
</tr>
</tbody>
</table>

Adler ED et al. Circulation 2009; 120:2597-2606
End-Stage CHF: Undertreated, Underrecognized

- Hospitalizations only improve symptoms in 35-50%
- Only 4% of patients dying of CHF get palliative care (40% for cancer patients)
- Average Karnofsky performance status: 32
End-Stage CHF: Undertreated, Underrecognized

- SUPPORT study: severe symptoms in last 48-72hrs prior to death
  - Breathlessness 66%
  - Pain 41%
  - Severe confusion 15%

- RSCD Study
  - Dyspnea 50%
  - Pain 50%
  - Low mood/depression 59%
  - Anxiety 45%

**In several studies, psychological/psychiatric symptoms most distressing**
CHF: Similarities to Cancer

- Dyspnea
- Cachexia
- Lethargy
- Pain
- Anxiety & Depression
- Decreased mobility, independence
- Insomnia
- Confusion
- More infections
- Hypotension
- Polypharmacy
- Fear of the future
- Multiple admissions
CHF: Differences from Cancer

- More edema
- Predicting death more difficult
- Mistaken belief that CHF more benign than cancer
- Less understanding of diagnosis and prognosis
- Less support groups, etc. for patients and families
Barriers to Palliative Care

- Often perceived as “chronic illness”
- Prognostication difficult
  - Disease trajectory
- Cardiology unfamiliar with palliative care practices
- Perceived inability of palliative care to manage
- Perception that must stop all meds
Barriers to Palliative Care

- Although mortality high, increasing number of patients living longer due to improvements in pharmacological, device, and cardiac surgical interventions
- Pacemakers/AICDs
- Resuscitation difficult subject
  - DNR written on 5% only (47% Ca pts, 52% AIDS)
  - 23% wanted DNR
Disease trajectory

1. a relatively stable primary phase needing routine chronic disease mgmt
2. one or more secondary phases of decline requiring increased utilization of hospital care + a variety of supportive and palliative care strategies
3. a terminal phase of inexorable deterioration lasting for days or weeks

- Death often unanticipated
The three main trajectories of decline at the end of life

- Cancer
- Organ failure
- Physical and cognitive frailty

Prognostication

- NYHA classification
- HF Survival Score
- Seattle HF Score
  - https://depts.washington.edu/shfm/
- EFFECT study
- Cardiovascular Medicine HF index
- What about... *simple clinical acumen*?!?!
Trajectory Triggers

- Recurrent episodes of decompensation within 6 months despite optimal tolerated therapy
- Malignant arrhythmias
- Frequent or continual IV therapies
- Chronic poor QOL
- Intractable NYHA class IV symptoms
- Cardiac cachexia
HFSA Recommendations

- End-of-life care for patients who have:
  - Advanced, persistent HF with symptoms at rest despite repeated attempts to optimize pharmacologic and nonpharmacologic therapy as evidenced by one or more of the following:
    - 3 or more hospitalizations per year
    - Chronic poor quality of life with inability to accomplish ADLs
    - Need for intermittent or continuous IV support
    - Consideration of assist devices as destination therapy
Patient and Caregiver expectations

- Frequent thoughts about death
- Fear of suffering
- Concerned about control of pain, dyspnea, other disease-related symptoms
- Concerns about inappropriate prolongation of life, maintaining autonomy, caregiver burden, relationships w/loved ones
- Patients and caregivers often lack understanding about symptoms of HF, management, disease trajectory
- Carers – anxiety, dread, guilt
Guidelines for Communication With Patients About Heart Failure
Prognosis and Plan of Care

Assessment:
Ask the patient what he or she understands about his or her condition.

Prognosis:
Be conscious that prognostic uncertainty is no excuse for a failure to communicate about the implications of advanced heart disease.

Preparation:
Prepare the patient emotionally for what to expect.
Provide approximate time estimates (eg, months or years?).
Talk about some likely scenarios.

Preferences:
Discuss healthcare proxy, goals if patient is permanently brain injured, cardiopulmonary resuscitation, ventilators, and location of care.
Discuss deactivation of ICD/cardiac resynchronization therapy/VAD, if applicable.

Planning for the worst:
Suggest getting financial and emotional affairs in order.
Help to mobilize community and family supports (eg, palliative care, home care, hospice referrals).

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Symptom Management

First: Continue Heart Failure Meds!
Dyspnea

- Positioning of pt
- Diuretics
- Afterload reduction – nitroglycerin formulations +/- hydralazine
- Inotropes
- Opioids – smaller doses than used for analgesia;
  - reduce preload and afterload
  - action in midbrain
Dyspnea

- Benzodiazepines - help symptoms of panic associated with breathlessness
- Oxygen – helps patient’s perception...
- Fans, air conditioning
Pain

- Pain inadequately dealt with in 90% (Gibbs 2002)
- Treat underlying cause-
  - Angina 41-77% (metanalysis 2006) – antianginals, stenting
  - Abdominal pain due to liver capsule stretching – diuretics. OMT.
- Opioids first-line agents for moderate to severe pain
  - No NSAIDS
  - Combination agents – such as Percocet, not recommended as adjuvants may prevent dose escalation
  - Methadone prolongs QT interval

Others: TENS, Spinal cord stimulators, etc.
Depression

- Prevalence of depression is > 30%,
  - mortality rates increased
- Treat underlying factors such as pain, dyspnea
- No evidence that treating depression reduces M&M, however, SSRIs and psychotherapy are both helpful in alleviating symptoms
  - Avoid drugs with high risk of drug-drug interaction, such as fluoxetine. Avoid TCAs.
  - Citalopram 10mg or duloxetine 15mg qd preferred
- Spiritual well-being and reinforcement
Fatigue

• Treat underlying causes
  • Anemia, infection, dehydration, electrolyte abnormalities, low nutritional intake, thyroid dysfunction, depression, sleep apnea

• Non-pharmacological techniques i.e. physical therapy/exercise (esp. for muscle wasting), training in aerobic exercise, energy conservation

• Some use methylphenidate
Edema

- Diuretics
- Compression stockings
- Extremity elevation
- Fluid, salt restrictions
- Paracentesis
- OMT
Nausea, Taste disturbance, Anorexia

- Reduced perfusion of intestines and sympathetics, stretching of liver capsule, many other factors all contributing...
- Small, frequent, easily digested, appetizing meals
- Pro-motility agents
- Can use drugs such as Marinol
- Vitamin supplements
Inotropes?

- No improvement in survival, but may provide symptomatic relief for prolonged periods of time
  - ACC/AHA: Class IIB indication for end-stage HF
- Some hospices provide inotrope therapy at home or inpatient, but cost-benefit analysis needs to be done
PPMs, ICDs, VADs

- Clinicians infrequently discuss ICD deactivation w pts
- As HF worsens, more shocks, causing significant pain, anxiety

- Cardiac resynchronization therapy does improve QOL

- VADS: a unique challenge. Better QOL but also a high rate of complications
OMT Techniques

- Lymphatic pumps
- Rib Raising (and other indirect rib techniques)
- Redoming the diaphragm
- Open the thoracic inlet
Integration of patient, family and clinician data regarding end-of-life care.

### Patients’ and carers’ experiences

1. High rate of psychological morbidity reported among patients
2. Carers experience anxiety, dread and guilt
3. Lack of communication regarding end-of-life issues between patients, carers and staff

### End-of-life preferences

1. Wide range across patient and carer groups
2. Mobility and age main deciding factors for patients; pain, quality of life and cognitive ability for carers
3. No discussion of preferences with staff

### Barriers to improving end-of-life care

1. Disease-specific
   - Unpredictable disease trajectory
   - Public perception of CHF as benign in comparison with cancer
2. Staff-specific
   - Cardiac staff need training in palliative care, including communication skills
   - Palliative care staff would benefit from training in CHF symptom management

Selman L et al. Heart 2007;93:963-967
Palliative care and Congestive Heart Failure

- Cost effective
- Discuss with patients/caregivers early on (especially cerebral function is optimized)
- Mutual education of staff
- Integrate as part of the team approach to comprehensive HF care; do not reserve for those who are expected to die within days or weeks.
Figure 1. Palliative care integrative model.


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Thank you!

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References

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- Selman L et al. Improving End-Of-Life Care for Patients With Chronic Heart Failure. Heart, 2007; 93:963-967.
In Memory

Myron Howell, D.O., FACOFP