The Patient with Advanced Heart Failure: Bridging the Gaps in End of Life Care

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Conflict of Interest

• None
Acknowledgments: It takes a village!

- Dr. Susanna Mak
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- Bhadra Lokuge
Learning Objectives:

1. Review the basics of Heart Failure;
2. Understand the challenges in the palliative management of patients with Heart Failure;
3. Assess and manage symptoms in End-Stage Heart Failure;
4. Understand the challenges in ICD deactivation.
Learning Objective #1: Basics of HF

Pathophysiology
MUSCLE DAMAGE

LV Dysfunction

Muscle Remodelling
- Hypertrophy
- Oxidative stress
- Fibrosis
- Apoptosis

Neuro-Hormonal Activation
- RAAS
- Norepinephrine
- SNS
- TNF α
- Inflammatory
- Na and Water retention

End organ hypoperfusion
- Renal dysfunction
- Confusion
- Fatigue
- GI dysfunction

Symptoms
- Edema
- Ascites
- Anorexia
- Early satiety
- RUQ pain
- Dyspnea

Symptoms
- Renal dysfunction
- Confusion
- Fatigue
- GI dysfunction

Symptoms
- Edema
- Ascites
- Anorexia
- Early satiety
- RUQ pain
- Dyspnea
NYHA CLASS

Class I: Symptoms with more than ordinary activity

Class II: Symptoms with ordinary activity

Class III: Symptoms with minimal activity
  • Class IIIa: No Dyspnea at rest
  • Class IIIb: Recent Dyspnea at rest

Class IV: Symptoms at rest
AHA CLASS - ACC/AHA

A - Risk factor or predisposition (no structural disease)
B - Structural disease, no symptoms
C - Disease and symptoms at any time
D - Disease and requires advanced treatment (ICD, LVAD)
Figure 1. Stages in the evolution of HF and recommended therapy by stage.

- **Stage A**
  - At high risk for heart failure but without structural heart disease or symptoms of HF
  - Examples: Patients with hypertension, coronary artery disease, diabetes mellitus, or patients using cardiotoxins or with FHx CM
  - Therapy: Treat hypertension, encourage smoking cessation, treat lipid disorders, encourage regular exercise, discourage alcohol intake, illicit drug use, ACE inhibition in appropriate patients

- **Stage B**
  - Structural heart disease but without symptoms of HF
  - Examples: Patients with previous MI, LV systolic dysfunction, asymptomatic valvular disease
  - Development of symptoms of HF
  - Therapy: All measures under stage A, ACE inhibitors in appropriate patients (see text), beta-blockers in appropriate patients (see text)

- **Stage C**
  - Structural heart disease with prior or current symptoms of HF
  - Examples: Patients with known structural heart disease, shortness of breath and fatigue, reduced exercise tolerance
  - Therapy: All measures under stage A, drugs for routine use: diuretics, ACE inhibitors, beta-blockers, digitalis, dietary salt restriction

- **Stage D**
  - Refractory HF requiring specialized interventions
  - Examples: Patients who have marked symptoms at rest despite maximal medical therapy (e.g., those who are recurrently hospitalized or cannot be safely discharged from the hospital without specialized interventions)
  - Therapy: All measures under stages A, B, and C, mechanical assist devices, heart transplantation, continuous (not intermittent) IV inotropic infusions for palliation, hospice care

Committee Members et al. *Circulation.* 2001;104:2996-3007
New Categories:

**HFrEF**
- EF < 50%

**HFpEF**
- EF normal
- Challenging
- Similar morbidity and mortality
- Older age, women, HTN
Treatment Overview

B Blockers
ACE I/ARB
Diuretics
  - Loop
  - Thiazide
Nitrates
Salt and fluid restriction
Adjunctive Therapy

Exercise program
Sleep study for obstructive sleep apnea
EPO for anemia
Vaccinations for influenza, pneumocococcus
Patient and family education
End organ hypoperfusion
  - Renal dysfunction
  - Confusion
  - Fatigue
  - GI dysfunction

Symptoms
  - Edema
  - Ascites
  - Anorexia
  - Early satiety
  - RUQ pain
  - Dyspnea

Muscle Remodelling
  - Hypertrophy
  - Oxidative stress
  - Fibrosis
  - Apoptosis

LV Dysfunction

ACE Inhibitors

Beta blockers

Neuro-Hormonal Axis

↑RAAS
↑Norepinephrine
↑SNS
↑TNF α
↑Inflammatory
Na and Water retention
Other treatments

Cardiac Resynchronization Therapy

Implantable Cardiac Defibrillators (ICDs)

LVAD Left Ventricular Assistance Device

Transplant
Learning Objective #2

Challenges to Traditional Palliative Care Model

Trajectory
Prognostication
Trajectory: Oncology

Onset of incurable cancer

Possible hospice enrolment

Often a few years, but decline usually < 2 months

Death
Excellent

Physical Function

Time

Death

Heart Failure Care

Palliative and Supportive Care

1

2

3

4

5

Sudden Death Event

Transplant or Ventricular Assist Device

Temmy Latner Centre for Palliative Care

Goodlin, SJ Am Coll Cardiol 2009;54:386–96
A Tale of Two Illnesses

Cancer

- Chemotherapy
- Often a transition point
- Public awareness that cancer can cause death

Heart Failure

- HF medications continue
- No transition points
- Little awareness of prognosis in HF

**Diagram:**
- **Cancer:**
  - Onset of incurable cancer
  - Possible hospice enrolment
  - Often a few years, but decline usually < 2 months
  - Death

- **Heart Failure:**
  - 1. Heart Failure Care
  - 2. Palliative and Supportive Care
  - 3. Transplant or Ventricular Assist Device
  - 4. Sudden Death Event
  - 5. Death

**Mount Sinai Hospital**

Joseph and Wolf Lebovic Health Complex

Temmy Latner Centre for Palliative Care
Prognostication:

Prognostication underlies the infrastructure in palliative care

But, in HF - prognostication defies us!
More than 100 variables have been associated with mortality and rehospitalization in heart failure

General
- Age, diabetes, sex, weight (BMI), etiology of HF, comorbidities (COPD, cirrhosis)

Laboratory markers
- Na, creatinine (and eGFR), urea, BUN, Hgb, % lymphocytes, uric acid

Urine
- NGAL - neutrophil gelatinase associated lipocalin

Biomarkers
- BNP, NT pro BNP, troponin, CRP, cystatin C, GDF-15 (growth differentiation factor), serum cortisol, TNF, ET, NE, midregional-pro-adrenomedullin (MR-proADM), pro-apoptotic protein apoptosis-stimulating fragment (FAS)

Medication
- Intolerance to ACEI, diuretic dose
- FC IV
  - Especially if sustained > 90 days
  - 6 minute walk

Cardiopulmonary markers
- Peak VO2, % predicted, VE/VCO2, AT, workload, systolic BP < 130, HR recovery

Clinical Exam markers
- BP (admission and discharge), heart rate, JVP, +S3, cachexia
- Depression
- Obstructive sleep apnea
- Echocardiogram parameters (LV, LA, RA), sphericity, RVEF, LVEF

Hemodynamic markers
- PA pressures, CO, CI, MVO2

Endomyocardial biopsies
- Microarrays transcriptomic biomarkers

Marital status

WHAT SHOULD YOU DO ?????
Consistent Predictors

Increasing age
Lower ejection fraction
Higher NYHA class

Hyponatremia
Elevated and rising BUN
Repeated admissions to hospital

From Selby, D. 2008
Another way to think about it:

Significant cardiac dysfunction with:
- Marked dyspnea and fatigue
- End organ hypo-perfusion at rest
- Symptoms with minimal exertion
- Maximal medical therapy

AHA Stage D - refractory symptoms

Goodlin et al, Journal of Cardiac Failure Vol. 10 No. 3 2004
Yet another way:

Assess knowledge, educational needs, goals and symptoms

Provide care based on:
- FUNCTION and NEEDS, not prognosis
Results in fewer referrals to PC

In a 2012 study of PCU admissions in Toronto,

Few HF admissions
Late admissions
Because we know:

Palliative Care strongly advocated
  • ACC/AHA Practice Guidelines
  • European Society of Cardiology
  • Heart Failure Society of America
  • Canadian Cardiovascular Society

Needs well-documented in many studies

Palliative Care specialists often not involved
Learning Objective #3:

Assessment and Management of End Stage Heart Failure: The Role of Palliative Care
OR...

So we know what it is and why it’s tricky and that they need care
SO WHAT CAN I DO???
Palliative Care Interventions

1. Assess patient and family understanding
2. Assess and treat symptoms - don’t forget mood
3. Maximize HF treatments - collaborate
4. Assess the psychosocial stressors
5. Determine patient’s goals of care
6. Assist with decision-making and advanced care planning
7. Education throughout
1. Patient and Family Understanding

Basic skills we already have...

Often requires education

Best done with family members

How much information do they want?
2. Assess and Treat Symptoms

- Dyspnea
- Depression
- Anxiety
- Insomnia
- Fatigue
- Nausea
- Pain
Edmonton System Assessment Scale (ESAS)

Please circle the number the best describes each of the following symptoms you are experiencing right now (at time of assessment):

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
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<td>Best feeling of well-being</td>
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<td>No shortness of breath</td>
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<td>Other problem (describe)</td>
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<td>Least possible other symptom</td>
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</table>
2. Assess and Treat Symptoms

Dyspnea
Depression
Anxiety
Insomnia

Fatigue
Nausea
Pain
Dyspnea

Rule out reversible cause if appropriate
Maintain cardiac medications
Diuresis if congestion
Titrate O2 if symptomatically helpful
Non-pharmacologic management
Opioids appropriate in this population
Continue HF medications

Evidence exists for use of:
- ACE Inhibitor - continue to use
- ARB - continue to use
- B Blocker - continue to use
- Aldosterone blocker - continue to use

Try to keep in this patient population
Diuresis suggestions: No Guidelines

Double Loop Diuretic
Change Frequency
Monitor symptoms, weight, BP, Creatinine PRN
Reassess in 2 - 5 days
If no improvement, add 2nd diuretic
Give HCTZ or Metolozzone 30 mins prior
K supp if good urine output
If no improvement, consider IV dosing or ED
Home diuretic protocol

For patients whose goals of care are to avoid hospitalization and invasive testing and monitoring

Can work with CCAC to develop a home-based protocol
Change in Patient Symptoms/Signs

- Dyspnea
- Orthopnea
- Edema
- Weight gain

On history ask about:
- Medication non-adherence
- High salt
- Infection
- NSAIDs

ASSESSMENT

On exam:
- Increased JVP
- Increased ‘crackles’
- Increased peripheral edema
- PICC line

Heart Failure Decompensation

No

Uncertain

Initiate RN daily monitoring x 7 days

If HF decompensation

Heart Failure Decompensation

MANAGEMENT

1. Order: RN to monitor symptoms, vitals, ± weight, and call MD daily x 7 days (see order template link)
2. Consider: Labwork, dietary counseling, foley catheter, IV line, IV supplies
3. Escalate diuresis: See next step for outline, page 2 for details
4. Consider: Call to cardiologist to inform

Escalation of Oral Therapy

Consider escalation of oral therapy if:
- Success with previous oral escalation
- Patient preference
- Bridging to delivery of intravenous therapy

Oral escalation guidelines - See next page

Initiate Intravenous Therapy

Consider IV if:
- Unresponsive to previous oral escalation
- Already on high dose therapy (>200 mg/day)
- Known resistance to diuretics
- Renal insufficiency
- Shortness of breath at rest

4-day IV dosing guidelines - See next page

Based on Goals of Care consider:
- Reassessment in HF clinic
- ED/Inpatient management
- Transition of therapy to end-of-life pathway

Symptom improvement

- Supplement K
- Resume previous PO flurosemide dose
- Consider increasing PO flurosemide dose
- PICC line if anticipate reoccurrence

Leave protocol
### Escalation of Oral Therapy

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<tr>
<th>Current Daily Dose</th>
<th>Suggested New Dose</th>
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<tr>
<td>&lt;40 mg/d</td>
<td>40 mg BID</td>
</tr>
<tr>
<td>40 to 120 mg/d</td>
<td>80 mg qAM/40 mg qPM OR 80 mg BID</td>
</tr>
<tr>
<td>120 to 240 mg/d</td>
<td>120-160 mg BID</td>
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<tr>
<td>&gt;240 mg/d</td>
<td>160 mg BID</td>
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#### Day 3-5 Reassessment

- **Weight Decreasing**
  - Patient Improving: Continue current dose Administer kdur Can consider stepping down oral therapy
  - Weight Unchanged or Increasing: Continue current dose Consider add on therapy

#### Day 7 Reassessment

- **Weight Decreasing**
  - Patient Improving: Continue current dose Administer kdur Can consider stepping down oral therapy
  - Weight Unchanged or Increasing: Increase current dose Consider add on therapy Consider IV diuretics

#### Add on therapies to consider

- **Metolazone**: 2.5-5mg/d x 3 days 2.5-5mg/d, M, W, F Metolazone can be very effective Limit to short, 3 dose trials and reassess
- **Hydrochlorothiazide**: 12.5-50 mg/d

### Initiate Intravenous Therapy

<table>
<thead>
<tr>
<th>Day 1</th>
<th>Current Daily Dose</th>
<th>Suggested New Dose</th>
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<tbody>
<tr>
<td>≤120 mg/day</td>
<td>40 mg iv BID</td>
<td>80 mg iv BID Consider add on therapy</td>
</tr>
<tr>
<td>&gt;120 mg/day</td>
<td>80 mg iv BID</td>
<td>Consider add on therapy</td>
</tr>
</tbody>
</table>

#### Day 2 Reassessment

- **Weight Decreasing**
  - Patient improving: Continue current dose Administer kdur
  - Weight Unchanged or Increasing: Continue current dose Consider add on therapy

#### Day 3 Reassessment

- **Weight Decreasing**
  - Patient improving: Continue current dose Administer kdur Can consider stepping down to PO
  - Weight Unchanged or Increasing: Increase 40 BID to 80 iv BID Increase 80 BID to 120 iv BID Consider add on therapy

#### Day 4 Reassessment

- **Weight Decreasing**
  - Patient improving: Continue current dose Administer kdur Can consider stepping down to PO
  - Weight Unchanged or Increasing: Increase 40 BID to 80 BID Consider add on therapy Can continue beyond 4 days

#### Add on therapies to consider

- **Metolazone**: 2.5-5mg/d x 3 days 2.5-5mg/d, M, W, F Metolazone can be very effective Limit to short, 3 dose trials and reassess

**STOP THERAPY AT ANY TIME IF:**
- Unacceptable biochemical derangement
- Symptomatic Hypotension
- Total of 6 days of therapy without symptomatic response
Oxygen

May be helpful

If not able to do sleep study, can try nocturnal oxygen
Use opioids for dyspnea

If diuresis not sufficient, opioids are effective in this population

Low dose, prn for intermittent dyspnea or pain

e.g. MS 2.5 mg po q 1 hr prn

e.g. Hydromorphone 0.2 - 0.5 mg q 1 hr prn
Depression

Common - assess for it

SSRIs recommended
Insomnia - Multifactorial

May be related to anxiety from dyspnea

Ensure good education re: dyspnea management
Fatigue

Volume overload

Myopathy and Cachexia

  Neurohormonal abnormalities
  Catabolism due to inflammatory mediators

Sleep-disordered breathing

Pain (>70%)

Depression (60%)

Comorbidities

Circulation 1995;91:559 - 61
Am J Crit Care 2008;17:124 -32
Fatigue

Manage comorbid reasons for fatigue, then

Can use methylphenidate - monitor HR and BP for tachycardia, hypotension, arrhythmias
Nausea

Gastroparesis
Intestinal edema
Reduced intestinal blood flow
Hepatic congestion
Try metoclopramide - consider s/c route
Avoid dexamethasone
Pain

Common in this population
Etiology not well studied
Multiple sources likely
Tylenol for mild pain
Opioid for moderate to severe pain

Avoid NSAIDs (worsening renal status)
Chest Pain

Nitroglycerin sublingual (as usual) x 3

If not effective, fentanyl sublingual 25 - 50 μcg x 3 q 20 mins

If not effective, add s/c hydromorphone

If pain frequently, consider a standing dose of opioid
Hypotension

If symptomatic hypotension (presyncope):

- Don’t change if low BP and no symptoms
- Try changing timing of medications
  - give at night; stagger doses

If need to decrease or eliminate for symptomatic hypotension, start with:

- CCB ➔ alpha blocker ➔ nitrate ➔ hydralazine ➔ BBlocker ➔ aldosterone antagonist ➔ ACEI ➔ ARB
Managing acute HF Decompensation

Assess for factors that may have aggravated HF

- NSAIDs, diet indiscretion, medication compliance, infection, anemia, arrhythmia,

Adjust diuretics as needed, allowing BUN/creatinine to rise

Once all medications optimized, use opioid for refractory dyspnea.
Assess Psychosocial Burden

Similar to the assessment for all our patients...

• Caregiver burden often high
• Make use of multidisciplinary team to support patient and family

Major concerns of patients

Not to be a physical or emotional burden
To an adequate plan of care and health services available to look after you at home upon hospital discharge
Information communicated by doctor in an honest manner
Objective 4:

Advanced Care Planning

Speak Up Campaign

ICDs
Talk to your doctor or nurse practitioner about **Advance Care Planning**

What would happen if you were sick or injured and could not tell doctors what kind of care you wanted?

Who would speak for you and make decisions for you?
Advanced Care Planning

Similar to “typical” discussions except...

• These patients often less involved in decision making than those with cancer;
• Don’t associate symptoms with cardiac status;
• History of recovery from exacerbations;
• History of helpful admissions, unlike oncology;
• Often need education first before goals clear
• How to translates goals into action -
  - Harder to get HF care at home

BMJ 2002;325: 929–33
JAMA 1998;279:1709–14
Advanced Care Planning

More limited access to supports that depend on prognosis

- Home Care
- Home Palliative Care

Limited availability of advanced therapies outside acute hospital setting

- Parenteral diuretics
- Inotropes
Advanced Care Planning

Action plans for unforeseen events

• “Things will not always go according to plan…”

Make sure the family is present

• Family member concerns can be a major barrier to discussion

Refer to existing ACP resources

• “Speak Up campaign”

Aleksova et al. [Abstract] CCC Toronto, October 2013
http://www.advancecareplanning.ca
Arch Intern Med 2004;164:1999-2004
ICD Deactivation - Challenges

Deactivation rarely discussed with patients

- <45% even after DNR
- 8% shocked within minutes of death

Patients perceive a dependence on ICD Action, not omission

Am Heart J 2002;144:282–9
Ann Intern Med 2004;141:835-8
ICD Deactivation - Pearls

Distinguish pacing from defibrillation

QOL will not improve

“I would recommend that...”
  • “People who benefit from ICDs are...”
  • “People who do NOT benefit from ICDs are...”

Emphasize ongoing care
ICD Deactivation

Contact ICD clinic for information about deactivation

Think about this in advance of last hours

Find out where magnets are kept
Summary

Today, I’ve tried to show you gaps and challenges

And tried to start to help you bridge those gaps

New and changing quickly...
References

Oxford Press.  Supportive Care in Heart Failure. James Beattie and Sarah Goodlin Eds.

2011 Canadian Cardiovascular Society HF Guidelines