Heart Failure Palliative Care

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Heart Function Team at TGH

- Follow 1800 outpatients with CHF:
  - NYHA III or IV – 596 (33%)
  - NYHA IV – 227 (13%)

- Annually at TGH:
  - 25 HTx
  - 20 LVAD

- Average Age of patients in our clinic = 55yrs

- Clinical research on HF EOL care
Heart Failure in Canada

• Heart failure in Canada:
  – 500,000 Canadians are living with heart failure
  – 50,000 patients diagnosed each year

• Worsening CHF associated with increased risk of death and/or hospitalization

• In Ontario hospitalized pts with NYHA IV HF
  – Median survival of 2.4 yrs
  – Mortality rate 33% 1 yr; 66% 5 yr

Ko et al, Am Heart Jour 2008
Disease Course: Stage C, D

Goodlin JACC 2009
Stage D Heart Failure

- Despite maximal medical therapy patients have significant cardiac dysfunction with:
  - marked symptoms of dyspnea, fatigue at rest
  - end-organ hypoperfusion at rest

- Specific predictors of poor outcomes:
  - NYHA IV, Na < 132, Cr > 200, Intolerant to ACEi, BNP, low BP & EF, 2+ hospitalizations in 6 mths

- Candidate for advanced surgical therapies?
Stage D Heart Failure
Quality of Life

• Quality of life is poor
• High symptom burden
  – Dyspnea, fatigue and sleeplessness
  – Experience as many as 15 symptoms/wk
• Significant functional limitations
• Depression and/or cognitive impairment – 30%
• Patients are willing to take significant risks and trade considerable time to improve their health.
Stage D Heart Failure

What We Do......

• Reassess goals of care in light of diminished life expectancy
  – Consider advanced therapeutic options e.g. Tx/VAD
  – Remember the math........

• Readdress symptom control → change direction of care → Quality of Life

• Consider expanded interdisciplinary team
  – Integrate palliative care

Hauptman et al, Archives of Internal Medicine: 2005 Palliative care in HF;
Goodlin JACC 2009; Hunt et al, Circulation 2009
HF Patient Preferences for EOL Care

Cross-sectional survey of hospitalized HF NYHA IV pts (n=106)

1. Avoidance of life support
   - 44% preferred a home death

2. Support for family caregivers
   - Caregiver burden was an obstacle to care in the home

3. Honest communication
   - 11% had discussed life expectancy with MD
   - 43% had not discussed resuscitation preferences

4. Relief of Symptoms

Strachan et al, CJC 2009(CARENET)
HF Patient Preferences for EOL Care

Qualitative study (n=20) NYHA III/IV patients:

1. Relief of symptoms
2. Not to be a physical or emotional burden
3. Adequate support and care at home
4. Open and honest communication
5. Adequate information about the disease, including the risks and benefits of treatment options
6. Doctor’s who discuss illness and answer questions in a way that you understand
7. Trust and confidence in the doctors looking after you

Caldwell et al, Can J Cardiol;2007
Heart Failure Guidelines for EOL Care
Include Patient Preferences

Guidelines for HF EOL
1. CCS 2006 (update 2011)
2. ACC/AAHA 2009
4. HFSA – Consensus Statement 2004

Common Concepts
1. Symptom management
2. Communicate prognosis
3. Advance care planning
4. Community based care
5. Interdisciplinary and collaborative care planning
Despite This......

- HF EOL pts more likely to be admitted to ICU
  - receive life-sustaining treatments
  - receive do-not-resuscitate orders later in their hospital course than do patients with metastatic cancer

- 73% of patients who die, die in hospital
  - 20% of these in specialized care units
  - Seriously ill much less likely to be referred to palliative care
  - ADHERE registry only 1.6% of hospitalized pts referred to hospice care

Providing HF Palliative Care is Challenging

1. HF symptom management strategies – aggressive?
2. Prognostic uncertainty
3. Measuring disease severity & mortality
4. Providing care is resource-intensive
5. Collaboration across teams
Symptom Management

Proportion of HF Patients at EOL who experience:

- Pain – 50%
- Dyspnea – 43%
  - Increased to 63% within three days of death
- Mood disturbance – 59%
  - 36.5% major affective disorder
  - 25.5% minor
- Anxiety – 45%

Koenig HG. Gen Hosp Pshcy 1998;20:29-43
Symptom Management

There are no RCT of medical **therapies** for CHF EOL

- Nitrates – relieve congestion, dyspnea
- Lasix – relieve congestion, dyspnea
- Opiods – reduce sensation of dyspnea
- O2 may improve dyspnea
- Treat depression (SSRI), insomnia
- Inotropes:
  - No oral inotropes currently approved
  - IV inotropes – increased risk of death
- Consider withdrawal of treatments with no benefits and potential side effects
Symptom Management

IV Inotropes & Diuretics provide symptom relief
BUT

✓ Increase the complexity of care in the home
  • Equipment
  • Coordination of visits

✓ Are associated with acute/critical care

✓ Alter usual vital sign parameters
  • Implications for staff education and maintenance of skills
Prognostic Uncertainty

1. Prognostic uncertainty in CHF
   - ++ clinical factors associated with poor prognosis
   - Prediction models lack precision in Stage D HF

2. Patients consistently over-estimate survival
   - do not perceive themselves at EOL
   - Success of CHF “rescue” reinforces perceptions

3. Symptoms and QL don’t always correlate with disease severity
Communicating Prognosis
What We Do........

1. At time of diagnosis:
   - Identification of SDM
   - Introduce ACD/Living Will

2. Progression to Stage D CHF:
   - Discuss ACD
     - EOL preferences
     - Resuscitation preferences

3. Review with significant changes/events & prn:
   - Admission to hospital, ICD shocks
   - Review EOL preferences
   - Palliative Care
Advance Care Planning

Survey in our CHF clinic (n=41):

- 68% NYHA II/III
- 76% had a written will
- 88% had identified a SDM

Habal et al, Can J Cardiol 2011
Advance Care Planning

ICD Deactivation

Many patients misunderstand the role/function of the ICD
  – Rhythm management - a pacemaker
  – Perceive the ICD as benevolent
  – Deactivation = suicide

ﬂ Asking patients who are stable and “well” about deactivation may be counter-productive

ICD patients with a diagnosis of a terminal disease ICD deactivation as part of EOL discussions
  – 100% had device deactivated

Goldstein et al Jour of Gen Int Med 2007; Lewis et al AJM 2006
Advance Care Planning

Patient treatment preferences.....

1. Change over time
   - Functional decline
   - Potential outcomes affect decisions

2. Aren’t communicated
   - SUPPORT trial

3. Affected by the Family
   - Caregiver burden
Measuring Disease Severity and Mortality

Palliative care tools for determining disease severity and mortality – ESAS and PPS

- Developed for use in patients with cancer
- Do they predict disease severity & mortality in CHF?
- ESAS provides meaningful information regarding symptom severity and management
- PPS – most accurate in predicting early death
  - Poor discrimination of scores between 50-70%
Measuring Disease Severity and Mortality

Research with our clinic patients:

n= 78 NYHA III/IV HF outpts (60yrs; 60% male)

Instruments

– Disease severity – ESAS, MLHFQ, VAS
– Estimating Mortality – PPS vs SHFM

Results:

1. Very poor quality of life (mean MLHFQ score = 60)
2. Mean # of symptoms = 7, Mean ESAS score = 36
3. Mean PPS score = 70, no score < 40

ESAS = Edmonton Symptom Assessment Score; PPS = Palliative Performance Scale;
MLHFQ = Minnestoa Living with HF Questionnaire; VAS=visual analog scale; SHFM = Seattle Heart Failure Model
Measuring Disease Severity and Mortality

n= 78 NYHA III/IV HF outpts (60yrs; 60% male)

• Moderate correlation between ESAS and QL
  – Applicable to HF
  – Can be used to determine resources

• No correlation between PPS & SHFM
  – PPS likely over-estimates mortality
  – SHFM likely under-estimates mortality
  – Further study is needed

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Collaborative Care

Controlled trial of Comprehensive Care Team (n=50) vs GIM clinic (n=40) for pts with cancer, COPD, CHF.

**Intervention patients showed:**
- significant improvement in dyspnea, sleep & anxiety scores
- 74% received equipment/services they qualified for
- 69% would have liked services sooner

No significant difference in pain or depression scores – recommendations not implemented by family MD

Rabow et al Arch Int Med 2004
Technology and EOL in HF

Things to watch out for over next 5-10 years

1. ICD – growth industry
   - Review issues of turning off defibrillator portion of device in patients nearing EOL
   - AHA/ACC guidelines – Class I, Level C recommendation to provide end-stage heart failure patients with information on the option of turning off their ICD

2. LVAD as an alternative to heart transplant
   - Device withdrawal

Hunt et al Circ 2009
EOL Planning and Care Indicators

End-of-life planning and care – indicators

Potential key performance indicators

- Percentage of heart failure patients who have a documented advanced care directive
- Percentage of heart failure patients who have a proxy decision maker identified
- Percentage of heart failure patients who have a documented discussion on resuscitation preferences
- Number of reviews and revisions to a patient’s advanced care directive
- Percentage of heart failure patients receiving palliative care or a palliative care consult
- Percentage of palliative care and hospice patients who have heart failure
- Percentage of heart failure patients who have a documented assessment of caregiver needs

Measures of quality end-of-life planning and care:
- Patient- and family-centred decision making;
- Communication about disease course and care plan;
- Continuity of care;
- Emotional and practical support;
- Symptom management and comfort care;
- Spiritual support; and
- Caregiver well-being

Measure of family/patient satisfaction

Research funding in Canada directed to end-of-life planning and care in heart disease

Percentage of postsecondary curricula that include education in end-of-life planning and care

Percentage of professional licensing examination questions that relate to end-of-life care and ethical decision making

Percentage of heart failure patients who die in their place of preference

Howlett et al CJC 2010
If Only it Were this Easy!

“As soon as the sad music starts, I’ll discuss your condition.”