GOALS OF CARE AND ADVANCED HF MANAGEMENT

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Objectives

At the end of this interactive workshop, participants will be able to:

- Review goals of care with patients and informal caregivers through an empathetic and effective discourse.
- Provide supportive treatment for patients with advanced heart failure symptoms that are refractory to standard therapy.
- Avoid patient hospitalization and ER visits when nearing end of life.
Disclosure

None
I am a ....

A. Physician
B. Advance Practice Nurse or Nurse Practitioner
C. Registered Nurse
D. Occupational therapy, physio, speech, nutrition
Most of my clinical work is in:

A. Heart failure
B. General Cardiology
C. Electrophysiology
D. Internal Medicine
E. Palliative Care
The Heart Failure Epidemic

- Canadian heart failure data:
  - Prevalence: 500,000 individuals
  - Incidence: 50,000 new cases each year
- HF has a high mortality:
  - Median survival after HF diagnosis: 2.1 years
  - 5,000 deaths/yr in Canada (2008)
  - 10,000+ deaths/yr in Canada (2020) = more than 1 death every hour
LV dysfunction – Natural History

Mechanism of death:
40% SCD
40% ↑ CHF
20% Other

AHA Classification

Risk Factors  Asymptomatic  Mild  Moderate  Severe
Advanced Heart Failure - Definition

- Patients have significant cardiac dysfunction with
  - marked symptoms of dyspnea, fatigue
  - end-organ hypoperfusion at rest
  - or symptoms with minimal exertion despite maximal medical therapy
- AHA Stage D
- Refractory symptoms requiring specialized interventions to manage symptoms or prolong life

Goodlin et al, Journal of Cardiac Failure Vol. 10 No. 3 2004
Advanced Heart Failure – Mode of Death

- Drowning → Slow inexorable progressive death
  - increasing dyspnea and orthopnea
  - decreased blood pressure
  - depressed levels of consciousness
- Dropping → sudden cardiac death
- With progression of heart failure mode of death switches from drop → drowning

Carson et al, COMPANION JACC 2005
Trajectory of Care of Dying Patient

- Seriously Ill Patient
  - Recovery
  - Diagnosis of Dying

Uncertainty

Certainty

- Ongoing Care
  - Death
    - Bereavement

Prognosis!!
Challenges in Prognostication

- Excellent
- Palliative and Supportive Care
- Heart Failure Care
- Transplant or Ventricular Assist Device
- Sudden Death Event

Legend:
- Excellent
- Palliative and Supportive Care
- Heart Failure Care
- Transplant or Ventricular Assist Device
- Sudden Death Event
Do the Math!

- 5-10% of 500,000 Canadians with HF Stage D
- 25,000-50,000 patients with advanced heart failure
  - ~ 180 Transplants/year
  - ~ 80 VAD’s per year
- **Majority elderly i.e. >70**

23,740 → 48,740 pts with advanced HF and no life saving therapeutic option

Dying with HF in Canada

- Paradox between technology and comfort
  - Most patients want to die at home but die in hospital
  - Many HF patients (20% to 40%) have ICDs
  - As HF patients reach end-of-life (EOL), often subject to unnecessary, painful ICD shocks

- Unwanted use of technology at EOL linked to:
  - Poor quality of life, low satisfaction with EOL care, high levels of anxiety/depression in family members
  - High cost of care in last 6 months of life
Canadian Cardiovascular Society (CCS) Guidelines for End-of-Life and Palliative Care

<table>
<thead>
<tr>
<th>Recommendations from the 2006 CCS heart failure guidelines (5)</th>
<th>Grade of evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Patients with heart failure should be approached early in the heart failure disease process regarding their prognosis, advanced medical directives and wishes for resuscitative care. These decisions should be reviewed regularly and specifically after any change in the patient's condition</td>
<td>Level I, grade C</td>
</tr>
<tr>
<td>2. Substitute decision maker (proxy) should be identified</td>
<td>Level I, grade C</td>
</tr>
<tr>
<td>3. Where possible, a living will should be discussed with patients to clarify wishes for end-of-life care</td>
<td>Level I, grade C</td>
</tr>
<tr>
<td>4. As patients near the end of life, physicians should readdress goals of therapy – balancing quantity and quality of life, with a shift of focus to quality of life. Palliative care consultation should be considered</td>
<td>Level I, grade C</td>
</tr>
<tr>
<td>5. Psychosocial issues (e.g., depression, fear, isolation, home supports and need for respite care) should be re-evaluated routinely</td>
<td>Level I, grade C</td>
</tr>
<tr>
<td>6. Caregivers of patients with advanced heart failure should be evaluated for coping and degree of caregiver burden</td>
<td>Level I, grade C</td>
</tr>
</tbody>
</table>

Arnold et al 2006; CJC
Case Presentation - 1

- John, male, 86 y.o.
- Lives at home, osteoarthritis, frail
- Home care with PSW once a week, Meals on wheels
- More difficulty getting to clinic appointments
- SOB more easily, wife cannot take care of him as much
- 2 children who live out of town; 6 grandchildren
- 3 admissions for HF in the last 6 months
Case Presentation 1 (cont’d)

- PMHx
  - Ischemic CM (3 previous MI, CABG), NYHA FC III-IV
  - LVEF 25% - no ICD: previously discussed but patient refuses
  - Atrial fibrillation
  - Hypertension
  - DM type 2
  - CKD (Creatinine: 210 umol/L, eGFR: 30; urea: 21 mmol/L)
Case Presentation 1 (cont’d)

- Post-discharge visit (hospital for 9 days)
  - Improved on IV furosemide, weight returned to baseline
  - BP is 92/60 – no postural drop
- Meds: Bisoprolol 2.5 mg OD, ramipril 5 mg OD, furosemide 80 mg BID, Metformin 250 mg BID, rosvastatin 20 mg OD, Pantoprazole 40 mg OD, sertraline 50 mg OD, MVI. Spironolactone discontinued re: worsening renal function
How likely are you to have an EOL conversation with this patient at this point?

A. Not likely. I don’t have the time.
B. Somewhat likely. It depends if I have the energy...😊
C. Likely to discuss
D. Very likely – I will make the time
What do you think is the most appropriate venue for such prognosis discussions?

A. Annual check-up with family doctor.
B. Outpatient heart failure visit.
C. When admitted to hospital for heart failure exacerbation.
D. After referral to palliative care.
E. When death is imminent.
Known Gaps in EOL Communication

- Patients with HF want honest communication
- Canadian data from patients and families:
  - Poor understanding of technology associated with their resuscitation status
  - Most patients (85%) do not want CPR
  - Failure of healthcare providers to engage in EOL discussions with patients and families
  - Lack of discussions associated with striking (70%) discordance between patients’ expressed preferences and prescribed code status

Heyland et al, JAMA Int Med 2013; Strachan et al, CJC 2009
Communicating Prognosis
Communication about EOL occurs well before EOL is imminent

Interactive, iterative process – “Ask-tell-ask”

Ensure family is with them during the discussion
  - You can ask them to bring their family with them when you arrange the appt.

Communication techniques that promote trust
  - Take time, sit down, attend to context
Using “ask-tell-ask” review:

- HF trajectory; understanding of illness
- Acknowledge uncertainty, individual Rx response
- Treatment Optimization: What CAN be hoped for?
- Need for advance care directives (ACD) and substitute decision-maker
- Document and communicate
Follow-up

- Follow up in 4 weeks to assess retention of information. Do they have a plan?
- Be aware that patient preferences may change
- Be Intentional: Create & exploit opportunities
  - Change in health status / prognostic indicator (hospitalization may not be the best time)
  - Introduction of new therapy (i.e. ICD)
  - Notice/assess caregiver burden

- EOL Communication **IS NOT**
  - a single conversation
  - a DNR conversation
Annual Heart Failure Review
(Allen et al Circ; 2012)

Table 5. Selected Components That May Be Included in an Annual Heart Failure Review

- Discuss and document in ambulatory setting, review when admitted to hospital.
- Milestones:
  - Review prognosis, options, preferences
  - Include information on survival, functional ability, QL for both pt and caregiver
Goals of Care
Case 1 (cont’d)

- You arrange a clinic visit with John, his wife and one of his sons.
- You ask John what he understands about his illness, ask him how he has been coping with the frequent hospitalizations as well as his family.
- You ask him to describe his concerns and his hopes or expectations

Response: John understands his heart is weak and does not want more information about his illness

- Asking what is important for him – **Goals of care**
- John wants to stay at home, not come to appointments, who will help his wife when he becomes sicker, wants treatment for his heart but does not want to prolong life
Goals of care

- What other information would you need to assist in developing the plan of care?
- How should you manage his symptoms at this time?
- What arrangements/resources are available in the community for support at home including support for informal caregivers?
- If John worsens with symptoms of heart failure, what do you recommend considering he wishes to stay at home and no longer be hospitalized?
Goals of Care vs. Advance Care Planning

• **Goals of care:**
  - Maintaining comfort
  - Promote patient choices
  - Promotion of quality of life at end of life
  - Care for the patient’s and their families psychosocial and spiritual needs

• **Advance Care Planning**
  - Process on health care decisions which includes goals, values and preferences for future care.
Goals of Care – Frameworks

- Conversation guide – CARENET “Just ask” campaign
  http://thecarenet.ca/our-campaigns/just-ask-campaign
- Canadian Hospice Palliative Care Association “Speak up”
  1. Learn the patient’s understanding of their illness
  2. Consider offering education to improve their understanding
  3. Identify goals for the future
  4. Discuss treatments including risk and benefits
  5. Present options

Iterative process – Team approach – low risk / high value intervention
ICD Deactivation Discussions
Case Presentation 2

- 69 yo male presents with severe CHF/ VT arrest
- Elevated BNP 1345, Not a Tx or VAD candidate
- Echocardiogram: LVEF 25-30%
- ICD inserted (QRS 116)
- Prolonged hospital stay with clinical decline, edema Creatinine 425 mmol/L
- Nephrology consultation: ?dialysis
- Family asks what they should do about the ICD appt that was booked and that gets you thinking about the functioning ICD....
Over this past year how often have you discussed turning an ICD off with a patient who has stage D heart failure?

A. Never
B. 1-5 times/yr
C. 6-10 times/yr
D. 11-20 times/yr
E. > 20 times/yr
A Practical Approach
Mitar et al, Circ HF 2012

Sherazi et al 26
Survey
Single center
n=87
58% General internists
5% Geriatricians
14% Cardiologists
21% Other specialties
3% Unreported

- 74% had cared for a patient with an ICD and a terminal illness
- 46% questioned the legality of withdrawing ICD therapy
- 18% thought withdrawal was unethical/possibly unethical
- 22% were uncomfortable deactivating an ICD

Kapa et al 27
Survey
Multicenter
n=658
11% Lawyers
37% Patients
52% Physicians

- 98% of physicians agreed with ICD deactivation in terminally ill patients
- 20% of patients equated deactivation to physician assisted suicide
- 10% of lawyers equated deactivation to physician assisted suicide

Kramer et al 28
Survey
Single center
n=185
63% internists
7% cardiologists
7% pulmonary/critical care
4% geriatricians
10% unreported

- 48% felt that ICD deactivation was not morally equivalent to cessation of mechanical ventilation
- 20% thought ICD deactivation could expose them to legal liability
- 2% of had requested legal advice before deactivation
1. ICD deactivation is legal and morally acceptable

2. Develop and implement a conversational protocol for ICD deactivation discussions

3. Accept responsibility for ICD deactivation discussions

4. Include ICD deactivation discussions during advance care planning and EOL discussions
Some ways to initiate the discussion....

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<tbody>
<tr>
<td></td>
<td>One of the most difficult things is that it is hard to predict exactly what will happen in the next (hours, days, weeks, months, years)........</td>
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<tr>
<td></td>
<td>What’s your understanding of what is happening now /what this treatment could offer?</td>
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<tr>
<td></td>
<td>You seem worried about what might happen if you don’t get the device/go home/ SOB increases/ get into this situation again....Can you tell me more about that?</td>
</tr>
</tbody>
</table>
End-of-Life:
Transitioning to Palliative Care
When should we begin to discuss palliative care with patients with HF?

- At the time they are diagnosed with HF
- When they are NYHA Class IV
- When they are optimally treated and continue to deteriorate
- ONLY when they or their family member request it
“As soon as the sad music starts, I’ll discuss your condition.”
Case Presentation 3

- 64 yo male, previous MI severe 3VD no viability on MRI scan not a candidate for ACB
- NYHA III - optimized HF therapy, ICD/CRT
- September 2013: worsening CHF - intubated, tracheostomy with active Staph infection.
- Failed ventilator weans x 2
- CICU staff optimistic with patient and wife regarding possibility of transplantation/VAD.
- Their son wants him referred for an opinion regarding advanced surgical therapies.
What’s your most likely response?

A. Tell them him he is not a surgical candidate
B. Arrange transfer; call and warn the surgeon
C. Ask him what he/they understand about the situation.
D. Arrange a multidisciplinary family meeting
Palliative Care: a Tale of Two Cities

Cancer
- Start with curative or life-prolonging Rx
- Discontinue curative/life-prolonging Rx when focus changes to palliation
- Often clear transition point

Heart Failure
- Start with life-prolonging Rx
- Many curative/life-prolonging Rx continue when focus changes to palliation
- No clear transition point
- Prognosis-based palliation likely not possible
Using Heart Failure Instruments to Determine When to Refer Heart Failure (HF) Patients to Palliative Care (PC)

Shift focus from prognosis-driven to symptom-driven PC with a standardized approach to HF symptom management:

1. Use Edmonton Symptom Assessment System (ESAS) revised to measure number and severity of symptoms
   - Implement interventions for specific symptoms – re-evaluate
   - Multiple symptoms or symptom scores > 7 may require PC consult

2. QL measurements
   - If symptoms are adequately controlled, QL should improve
   - If QL does not improve may require PC consult

Trigger for PC referral becomes presence of unmanageable symptoms NOT survival time < 6 months

Timmons et al 2013 - Journal of Pall Care 2013
Edmonton Symptom Assessment System:
Numerical Scale
Regional Palliative Care Program

Please circle the number that best describes:

<table>
<thead>
<tr>
<th>Symptom</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
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<tbody>
<tr>
<td>No pain</td>
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<td>Not tired</td>
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<td>Best appetite</td>
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<td>Best feeling of wellbeing</td>
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<tr>
<td>No shortness of breath</td>
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<td>10</td>
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<tr>
<td>Other problem</td>
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<td>10</td>
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</tbody>
</table>

Patient's Name ___________________________ Complete by (check one)
Date ___________________________ Time ___________________________

☐ Patient
☐ Caregiver
☐ Caregiver assisted

BODY DIAGRAM ON REVERSE SIDE
Edmonton Symptom Assessment Scale and HF Quality of Life (n = 78)

- Designed to measure symptom severity with cancer patients.
- 10 symptoms rated on a 10 point scale.
- Provides individual symptom scores + overall symptom distress score.
- Moderate correlation with MLHFQ scores

![Figure 1: Relationship between the Edmonton Symptom Assessment Scale (ESAS) and the Minnesota Living with Heart Failure Questionnaire (MLHFQ) (r=0.483, p<0.01, n=78)](image)

Timmons et al Jour Pall Care 2014
What concerns you most about talking to patients about Palliative Care?

A. It will frighten them: they will think they are dying
B. They will think I am giving up on them and there is nothing more to do
C. It sends the wrong message about what we can do for them
D. I don’t really know how palliative care can help these patients
Who should coordinate the implementation of palliative care for patients with HF?

A. The palliative care team
B. The cardiologist
C. The heart failure APN/NP
D. Primary care team (MD/NP)
What should we say?

1. Clarify what the patient/family already knows
   - Clarify differences in HF & PC language & goals of care
   - Is the goal survival or comfortable death
2. Use consistent terminology & meanings
   - Palliative care, symptom control or comfort care, Survival or death?
   - Cautious use of euphemisms
3. Discuss preferences re place & mode of death
   - Consider emergency situations (EMS DNR order)
   - ICD deactivation
Model of Shared Decision Making Heart Failure

- Ethical and legal mandate to involve patients in medical decisions
- Recognizes that there are complex trade-offs in treatment decisions
- Addresses the ethical need to fully **inform** patients about the risks and benefits of treatments
- Involves clinicians working with patients to ensure that patients' **values, goals, and preferences** guide informed decisions that are right for each individual patient

**Figure 2.** Prognosis is not only about expectations for survival. There are multiple domains that are of varying importance to individual patients. Adapted from Spilker.38

Management

- Multiple symptoms – ESAR-r
- Consider repeating ESAR-r at each encounter to help informal and formal caregivers
- Engaging local resources
- Using a “Symptom Relief Kit”:
  - lorazepam s/l (anxiety, seizures)
  - Haloperidol (sc) (delirium, agitation,
Symptom Relief Kit

- Lorazepam sl (anxiety, seizures)
- Haloperidol (sc) (delirium, agitation)
- Atropine 1% ophthalmic Drops (terminal congestion or secretions) – give sublingually q3h prn
- Olanzapine orall disintegrating Tab (nausea)
- Scopolamine 0.4 mg/ml (terminal congestion/secretions) give sc q4h prn
- Acetaminophen 650 mg supp (temperature)
- Morphine or hydromorphone (emergency pain relief or dyspnea) sc
Dyspnea and Edema

- Loop diuretics:
  - Furosemide IV (up to 400 mg/day) – boluses vs infusion (3-20 mg/hour)
  - Consider subcutaneous infusion
  - Bumetamide PO (max of 10 mg/day)
  - Metolazone PO (2.5 – 5 mg/day)
  - HCTZ PO (25 – 50 mg/day)
<table>
<thead>
<tr>
<th>Other Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Pain</strong></td>
</tr>
<tr>
<td>Mild: acetaminophen; moderate to severe: opioids – avoid NSAIDS</td>
</tr>
<tr>
<td><strong>Fatigue</strong></td>
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<tr>
<td>Multifactorial causes; Methylphenidate PRN</td>
</tr>
<tr>
<td><strong>Insomnia</strong></td>
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<tr>
<td>Sleep hygiene – zopiclone?</td>
</tr>
<tr>
<td><strong>Nausea</strong></td>
</tr>
<tr>
<td>Domperidone 10 mg PO TID / sc metoclopramide 10 mg q 6h</td>
</tr>
<tr>
<td><strong>Constipation</strong></td>
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<tr>
<td>Prevention; senna, osmotic agent (PEG 3350); lactulose - cramps</td>
</tr>
<tr>
<td><strong>Anxiety</strong></td>
</tr>
<tr>
<td>Benzodiazepines – short acting (lorazepam)</td>
</tr>
<tr>
<td><strong>Hypotension</strong></td>
</tr>
<tr>
<td>Consider discontinuation of medication</td>
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</table>
Medical Assistance in Dying (MAID)

- Bill C-14
- Provide access to patients who request MAID
- Trained healthcare professionals
Advanced HF – Inotropic Support

- Dobutamine / Milrinone
- Improves functional status and symptom control but increases mortality
- Consider in select patients – non evidence based
- Stable on IV inotropes on the ward
- Eligible for Palliative Care Unit / Hospice Care
- Must have intact cognitive function
- Patient and family / friends are comfortable with palliative approach
- No CPR / Device activation
- PICC line
Conclusion

- Supporting informal caregivers (spouse, family, friends)
- Shifting focus from active treatment to supportive/palliative care (including discontinuation of meds)
- Clear understanding of goals of care and outcome – maintaining hope
- Ongoing exchange – discussion
- Multidisciplinary team – patient centered