Palliative care in Heart Failure
Shining a Light on EOL Communication

Catherine Demers MD MSc, Jane MacIver RN-NP PhD, Heather Ross MD MHSc, Patricia Strachan RN PhD, John You MD MSc

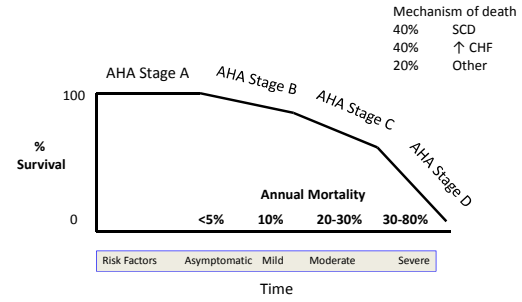
Objectives

1. Better understand **potential barriers to goals of care** discussions from cardiology healthcare providers (MDs, RNs, NPs, others) who care for patients with advanced HF in the hospital setting and outpatient clinic.
2. Identify **possible solutions** which would lead to improved communication.
3. Provide a **conversation guide** leading to the discussion of goals of care with patients with advanced HF.

The Heart Failure Epidemic

- Canadian heart failure (HF) 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



AHA Classification

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

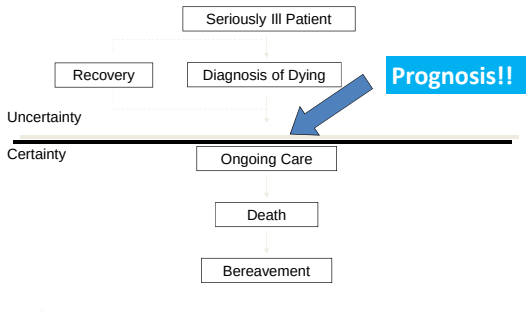
Goodlin et al, Journal of Cardiac Failure Vol. 10 No. 3 2004
Hunt SA et al JACC 2001;38:2101–13.

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



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

Hunt et al Circ 2009; Kirklin et al, JHLT 2010; 29:1-10; www.unos.org

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 2
Canadian Cardiovascular Society (CCS) guidelines for end-of-life and palliative care

Recommendations from the 2006 CCS heart failure guidelines (5)	Grade of evidence
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	Level I, grade C
2. Substitute decision maker (proxy) should be identified	Level I, grade C
3. Where possible, a living will should be discussed with patients to clarify wishes for end-of-life care	Level I, grade C
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	Level I, grade C
5. Psychosocial issues (eg, depression, fear, isolation, home supports and need for respite care) should be re-evaluated routinely	Level I, grade C
6. Caregivers of patients with advanced heart failure should be evaluated for coping and degree of caregiver burden	Level I, grade C

Arnold et al 2006; CJC

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

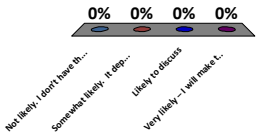
Communicating Prognosis

Case Presentation 1

- 78 year old female, severe CHF, LVEF 29% - clinic
- Optimized medical therapy (ACE-I, Beta blockers, MRA, diuretics)
- ICD upgraded to CRT-D
- 6 months later: frail, wheelchair, clinical decline, NYHA class IV symptoms
- Her 3 daughters are with her in clinic –they want to know: how bad is her heart failure? When will she feel better?
- AND……you're already 20 mins behind schedule

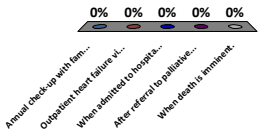
How likely are you to have an EOL conversation with this patient at this point ?

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.



EOL Communication Fundamentals
Set the Stage

- 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

EOL Communication Fundamentals
Map the Route

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

EOL Communication Fundamentals
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

Characterization of clinical status
Functional ability, symptom burden, mental status, quality of life, and disease trajectory
Perceptions from caregiver
Solicitation of patient values, goals, and general care preferences
Estimation of prognosis
Consider incorporating objective modeling data
Orient to wide range of uncertainty
Review of therapies
Indicated heart failure therapies in appropriate patients (BB, ACEI/ARB, AA, CRT, ICD)
Treatment of comorbidities (AF, HTN, DM, CKD, etc)
Appropriate preventive care, within the context of symptomatic heart failure
Planning for future events/advance care planning
Resuscitation preferences
Desire for advanced therapies, major surgery, hospice
Standardized documentation of the annual review in the medical record

BB indicates β-blocker; ACEI, angiotensin-converting enzyme inhibitor; ARB, angiotensin II receptor blocker; AA, aldosterone antagonist; CRT, cardiac resynchronization therapy; ICD, implantable cardioverter-defibrillator; AF, atrial fibrillation; HTN, hypertension; DM, diabetes mellitus; and CKD, chronic kidney disease.

- 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

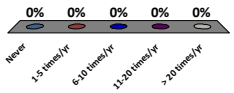
ICD Deactivation Discussions

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….

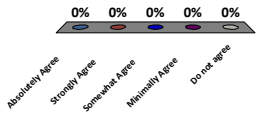
Over this past year how often have you discussed turning an ICD off with a patient who has stage D heart failure?

A. Never
B. 1-5 times/yr
C. 6-10 times/yr
D. 11-20 times/yr
E. > 20 times/yr



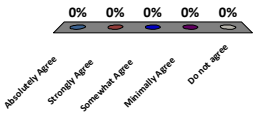
How strongly do you agree with the following statement: Turning off the ICD is unethical?

A. Absolutely Agree
B. Strongly Agree
C. Somewhat Agree
D. Minimally Agree
E. Do not agree



How strongly do you agree with the following statement: Turning off the ICD amounts to euthanasia?

A. Absolutely Agree
B. Strongly Agree
C. Somewhat Agree
D. Minimally Agree
E. Do not agree



ICD Deactivation Discussions
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	• 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

ICD Deactivation Discussions
A Practical Approach

Mitar et al, Circ HF 2012

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

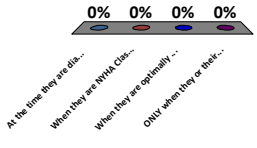
Some ways to initiate the discussion….

- 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)…….
- What's your understanding of what is happening now /what this treatment could offer?
- 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?

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

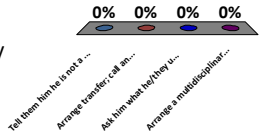


Case Presentation 3

- 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	Heart Failure
• Start with curative or life-prolonging Rx	• Start with life-prolonging Rx
• Discontinue curative/life-prolonging Rx when focus changes to palliation	• Many curative/life-prolonging Rx continue when focus changes to palliation
• Often clear transition point	• 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:

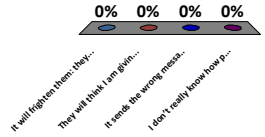
1. Use Edmonton Symptom Assessment System (ESAS) to measure number and severity of symptoms
   - Implement interventions for specific symptoms – re-evaluate
   - Multiple symptoms or symptom scores > 7 may require PC consult
2. QOL measurements
   - If symptoms are adequately controlled, QOL should improve
   - If QOL 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 – in press

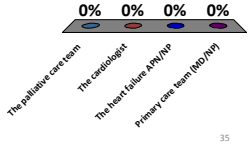
What concerns you most about talking to patients about Palliative Care?

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)



35

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