Palliative Care and Hospice: When and How for Patients with Heart Failure

AAHFN 12th Annual Meeting Scottsdale AZ
Ann Laramee MS ANP-BC ACNS-BC CHFN ACHPN
Nurse Practitioner
University of Vermont Medical Center
Burlington, VT

Objectives

1. Summarize the best evidence why and when to incorporate palliative care
2. Identify when to discuss and refer a patient to hospice
3. Describe strategies to help patients have prognostic awareness
4. Describe foundational palliative care skills for the patient with heart failure

Language to explain to colleagues and patients why palliative care is needed

Palliative Care

Patient and Family Centered Care that optimizes quality of life by anticipating, preventing and treating suffering.

Palliative Care throughout the continuum of illness addresses physical, intellectual, emotional, social, and spiritual needs.
Facilitates patient autonomy, access to information and choice.

- Interdisciplinary approach
- Prognosis – doesn’t matter
- Focuses on communication
- Shared decision making
- Advance care planning
- Provides relief from distressing symptoms
- Integrates psychological and spiritual aspects of care
- Support system to help families cope

- National Quality Forum and CMS
Hospice Care

- Service delivery system that provides palliative care for patients who have a limited life expectancy and require comprehensive biomedical, psychosocial, and spiritual support as they enter the terminal stage of an illness or condition*
- A subset of palliative care

*shift from disease modifying treatments including hospitalization to care focused on comfort and provided in home/outside of the hospital


Heart Failure Care Model

- HF DM Management
- Palliative Care
- Hospice
- Comfort care EOL care

Why is Palliative Care Important?

- Half of American over 65 are disabled and living with major chronic diseases
- In the next 35 yrs
  - 65+ will double (84 million)
  - 80+ will triple (31 million)
  - 90+ will quadruple (8 million)
- 10,000 Americans turn 65 everyday
- Recommending or proceeding with procedures or treatments that are not consistent with what matters to the patient is a patient safety issue that could and does lead to harm and sentinel events

Neuman T Henry J. Kaiser Family foundation Jan 2015
Dy SM Am J of Hospice & Pall Med 2015
Why is Palliative Care Important?

- Death rate ~50% in 5 years
- 10% of all deaths
- Following an index ADHF admission:
  - 30 day mortality ~11%
  - 60 day mortality + re-hospitalization 40-50%
  - One year mortality post HF hospitalization >30%
- Fewer than 12% of hospice patients have advanced HF
- Median LOS in hospice 15 days

Why is Palliative Care Important?

In the last 6 months of life of HF pts:
- 80% of patients hospitalized
- Average days in hospital: 20
- Average days in ICU: 4.6
- 36% die within one year of HF-related hospitalization

Where are we? There is Still Work to do!!

- Our guidelines recommend palliative care
  - Yancy et al 2013 ACC/AHA HF guidelines
  - Ponikowski et al 2016 ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure
  - Lindenfeld et al 2010 HFSA Comprehensive guidelines
  - Whellan et al 2014 Consensus Statement EOL care in pts with HF
- Yet important guidelines it is lacking
  - Stout et al 2016 AHA Chronic Heart Failure in Congenital Heart Disease: A Scientific Statement
After HF Hospital Stay: Symptoms Linger, Palliative Care Is Rare

- Fewer Than 10% of HF Patients Receive Palliative Care
  - Once learned about it, 66% interested
- Fewer than 1 in 4 pts familiar with palliative care
  - Thought only for cancer pts
  - Same as hospice
- Patients replied to a questionnaire about symptoms about 9 days after they were discharged. About half of the patients reported no improvement in fatigue (58%), dyspnea (42%), anxiety (41%), and pain (41%).

More Research is Needed - On Going Trials

- IMPACT-HF² Laura P. Gelfman, MD, MPH; Nathan Goldstein, MD & Marie Bakitas, DNSc, CRNP
  - Focus on research, clinical models and quality metrics/policy
- PAL-HF – Palliative Care in Heart Failure July 2016
  - Duke study, RCT, interdisciplinary 6 mo palliative care intervention 200pts, symptom relief, attention to spiritual concerns & ACP
- CASA – Collaborative Care to Alleviate Symptoms and Adjust to Illness in Chronic Heart Failure Dec 2016
  - RCT, intervention to improve symptoms and QOL by integrating palliative and psychosocial care into chronic care

ENABLE: Palliative Care Model for Older Adults with Heart Failure and Caregivers

- Aim: Evaluate a cancer-focused PC intervention into one that would be appropriate for rural-dwelling adults with Class III-IV HF and their caregivers
- Intervention: early, concurrent PC model, ENABLE (Educate, Nurture, Advise, Before Life Ends) phone and manual-based by PC APRNs. Phase I: Tailored for an HF population via lit review, expert consultation, and clinician small group interviews. Phase II: 11 patient/caregiver dyads to assess intervention feasibility and satisfaction.
- Results: feasible and well received by clinicians and HF patient/caregiver dyads, barriers & modifications identified, Dyads wanted it earlier in trajectory
Inpatient palliative care for HF pts is associated with improvement in symptom burden, QOL, and depressive symptoms

- RCT - PC consult with follow-up as determined by provider or standard care. 116 intervention/116 control from a large tertiary-care urban hospital were recruited over a 10-month period.
- Aim was to assess if inpatient PC for HF patients is associated with improvements in symptom burden, depressive symptoms, QOL, baseline, 1, and 3 months. Secondary outcomes included advance care planning, 30-day readmission, hospice use, and death.
- Improvements were greater at both 1 and 3 months in the intervention group in the summary scores for QOL, symptom burden and depression.
- Intervention group more likely to complete the ACP process after discharge.

A Randomized Pilot Trial to Improve ACP for LVAD Patients and Surrogates

- Aim: Examine feasibility, acceptability and prelim effects of an ACP intervention, SPIRIT-HF.
- Intervention: outpt pt/surrogate received structured, guided discussion from trained PhD nurse clinician in single 1hr session with 5 steps: 1. Assess representations; 2. Id gaps and concerns; 3. create conditions for change; 4. intro replacement info; 5. set goals, plan and summarize.
- Results: 29 dyads randomized all completed - feasible, all reported positive, benefited – most helpful able to express or clarify preferences for EOL care, learn about common scenarios, make sense of experience. Dyad congruence in GOC, mod effect on pt decisional support, no effect on surrogate decision making confidence.

Integrating Palliative Care in a TAVR Program

- Description of a Canadian TAVR program currently under evaluation of how they integrated palliative care.
- Reflects best practices and current evidence esp for those too frail and with sign comorbid conditions to have the TAVR.
- Introduced a palliative approach in assessment and education, measurement of symptoms, improved communication and followup and triggers for palliative care referrals.
Innovative Advance Care Planning Intervention Using Non-clinican with Heart Failure Inpatients

- Aim: feasibility of implementing multicomponent hospital based ACP intervention on completion of ACP forms among HF pts
- Intervention: nonclinican health educator using ed video about shared decision making and protocol to engage HF providers in ACP after hospitalization
- Results: 37 participants, majority found helpful and more likely to discuss with their provider about EOL preferences. Significant increase in completion of POLST after intervention.

Sadeghi B 2016 Journal of Palliative Medicine

Life of a patient with heart failure

Advanced Care Planning

- Advanced Directives
  - Health Care Agent or Proxy
  - COLST, MOLST, POLST - Care preferences
- Goals, Values, Hopes, Worries
- Preparedness planning
  - Disease specific plan
- Benefits vs. Burdens
- Shared Decision Making
  - Decision aids

Barriers to Integrating Palliative Care

- Uncertain prognosis, unpredictable trajectory
- Pts and providers over estimate prognosis
- Lack of training in palliative care and communication
- Pts unrealistic hope and lack of knowledge
- Clinicians fear alarming pts, create anxiety, depression, destroy hope and cause pts to give up the fight for life or saying wrong thing
- Disempowered pts
- Time pressures – conversations take time and are complex
- Silos of care
- Complex treatment options with complex tradeoffs
- Who does it PC, PCP or specialist

EOL conversations – Systematic review

- Patients do not perceive they have had a discussion
- Some want these conversations; some don’t
  - Sensitive, with honesty and repeated opportunities
- Patients prefer doctors initiate conversations
- Conversations between clinicians and pts focus on DM and EOL conversations not discussed
- So what to do?
  - Opportunities to discuss uncertain prognosis, risk of sudden death, their priorities and preferences for care
  - Balance optimism and realism
  - Offered at all stages of trajectory – ongoing dialogue
  - Need advanced communication skills
  - Done with an established relationship with commitment over time

Five Main Categories for Palliative Care
Conversations with HF patients

- Delivering bad news
- Discussing prognostic uncertainty
- Establishing goals of care
- Planning for End of life
- Discussing treatment options
Palliative Care Talk

• Delivering bad news – assessing prognostic awareness
  – “Tell me what you understand about what is happening with your heart”
  – Give a warning shot, “I am afraid I need to discuss something very important….. You are nearing the end of your life”
  – Wish statements “I wish this could be different…..”
  – Use lots of silence
  – “with this new information, what would be important for us to do for you?….what are your priorities at this stage”
  – “Knowing that time is short, what goals do you have for the time you have left—what is important to you? What do you/we need to do?”
  – “what worries you the most?”
  – May have to nudge
  – Respond to emotion – “I cannot imagine how hard this is for you”

Palliative Care Talk - continued

• Discussing prognostic uncertainty
  – Although I can’t give you an exact time, given your illness and condition, I believe you have (hours to days) (weeks to months). This is an average, some live longer and some live shorter
  – has anyone talked to you about what to expect?
  – the uncertainty of heart failure makes it very hard…..

• Establishing Goals of Care
  – I’d like to talk with you about possible health care decisions in the future. This is something I do with all my patients so I can be sure that I know and can follow your wishes. Have you ever completed an Advance Directive?
  – knowing you are living with a life limiting illness, what are you hoping for?
  – this hospitalization places you at a different place in your illness……I am worried and want to make sure we are providing you with the best possible care….Would you like to hear more about this?
  – What abilities in your life are so crucial you cannot live without them?

• End of life planning
  – If you don’t do as well as we hoped, what would be your specific wishes and hopes?
  – While we hope and work for the best, we should also have a plan in place to provide the best care we can if she is at the end of her life.

• Discussing treatment options
  – Would you like to hear what other patients experience living with heart failure
  – Remember how we talked about how when the ICD was not appropriate therapy?…well we are at this place now

Discussions with your Patients

• Excellent communications skills
  – Taking the pulse of the room
  – Active listening – be curious, don’t have an agenda, talk less listen more
  – Body language
  – Silence
  – Silence
  – Silence

• Ask - What have your doctors told you about your illness?
• Tell - Living with a life limiting illness is difficult
• Ask – Would you like to know what to expect?
Steps for Successful Advance Care Planning

- Prognosis in setting of uncertainty
  - Understanding needed to make right decisions
  - Offer broad ranges
- Engage pt/family in discussion of values and goals
  - How do they prefer info communicated?
  - Explore hopes and fears, what QOL means to them
  - Needed before the laundry list of interventions
  - Foundation for current and later reference for guidance
- Review and recommend reasonable options for further care
  - Including anticipated (dialysis) or well known therapies (transplant)
  - What ifs
- Timing – ideally outpt, early, regularly, annual review
- Revisit and review - milestones

Goals of Care – 3 Broad Categories

- Life prolonging
  - At any cost?
- Maintenance of function
  - Get home
  - Walking, thinking, seeing, doing
- Maximization of comfort
  - Exclusive emphasis?

Components Included in an Annual Heart Failure Review

Characterization of clinical status
- Function, symptom burden, QOL, disease trajectory
- Perceptions from caregiver

Solicitation of patient values, goals, and care preferences

Estimation of prognosis
- Consider models, discuss uncertainty

Review of therapies
- Indicated HF therapies
- Treatment of comorbidities (AF, HTN, DM, CKD, etc)

Planning for future events/advance care planning
- Resuscitation preferences
- Desire for advanced therapies, major surgery, hospice

Document

Stevenson LW, O'Donnell A. Advanced care planning: care to plan in advance. JACC Heart Fail 2015

Gillick MR J Med Ethics 2015 Re-engineering shared decision making

Sometimes living life to its fullest requires knowledge of its finitude

*Lewis Cohen MD, No Good Deed, 2010*

**Pendulum Coping**
Patients Struggle to Understand their Prognosis

![Diagram showing pendulum coping](image)

Jackson VA et al. 2013 J Pul Med

**For Hospice Enrollment for HF:**

- Severity of Illness
  - Severe LV dysfunction
  - Class IV symptoms despite optimal tx
- Recent clinical progression including any of:
  - 2 or more hospital or ED visits within 6 months
  - New dependence in ADLs
  - Renal, hepatic or CNS dysfunction without reversible cause
- Evaluation for advanced therapies
  - CRT, ICD, LVAD, Heart transplant
- Preference for comfort care over life sustaining treatment
Patient-centered communication: The 5 elements and associated tools
In Preparedness Planning

\[\text{If I hear you correctly...} \]
\[\text{So based on what you have told me...} \]
\[\text{This is a difficult conversation...} \]
\[\text{This can help your family...} \]
\[\text{Most people do very well, some encounter challenges...} \]
\[\text{At some point the pump may have “outlived” its purpose...} \]

Acknowledgement:
Ellin Gafford MD OSU

HF Prediction Models

http://depts.washington.edu/shfm/app.php

Canadian CV Outcomes - EFFECT Heart Failure Mortality Prediction

http://www.ccort.ca/Research/CHFRiskModel.aspx
Would You be Surprised if this Patient Died in the Next Year?

- Recurrent HF hospitalizations
- Decrease ACEI/ARB or beta blockers for hypotension or worsening renal function
- Persistent Class IV symptoms
- Lasix diuretic dose > 160 mg
- Frailty and co-morbidities, new cancer diagnosis
- Hyponatremia, cardiorenal syndrome
- BNP > 1000 or NT BNP > 4000
  - Predischarge BNP of >700 (NT pro BNP 7000) correlated with a risk of death of 31% in 1 month and 93% in 6 months (Logeart D JACC 2004)

Which one of your HF patients has >50% of dying in the next year?

Summary

- Know where your patient is on their trajectory/prognosis
  - Ask yourself the surprise question?
    - Hospitalization big clue
- Help your patient have prognostic awareness
  - Ongoing evaluation of goals at all stages of disease
  - Have the language
- All clinicians should be skilled in primary palliative care skills
  - Seeing from a new perspective
  - Goals of care/ Advance care Planning conversation
- A goal without a plan is just a wish