Advance Care Planning with Heart Failure: Results of a Primary Care Practitioners Needs Survey

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Objectives

- Obj. 1: Explain the survey results: Primary Care Practitioner Needs Assessment when caring for patients living with chronic heart failure.
- Obj. 2: Discuss evidence based heart failure palliative care, specifically advance care planning and disease preparedness interventions with particular attention to navigating an uncertain trajectory.
- Define and differentiate between palliative care and hospice for chronic advanced heart disease.
- Identify how early concurrent palliative care in the chronic heart failure population can improve patient outcomes.
Definition of Heart Failure

- Complex clinical syndrome that can result from any structural or functional cardiac disorder that impairs the ability of the ventricle to fill with or eject blood.

ACC/AHA 2013 Chronic HF guidelines

Heart Failure Facts

- US prevalence – 5.7 million
- At 40 years of age, lifetime risk of developing HF for men and women 1 in 5
- 30 day readmission rate about 24%.

Roger, A S GO et al Circulation 2011
Epidemiology of Heart Failure

- More deaths from heart failure than from all forms of cancer combined
- 4.7 million symptomatic patients; estimated 10 million in 2037
- Incidence: About 550,000 new cases/year
- Prevalence is 1% between the ages of 50 and 59, progressively increasing to >10% over age 80

Heart Failure Facts

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


www.cdc.gov/nchs/data/nhhcd/hospice
Hauptman, Goodlin et al. 2007
Symptoms of Heart Failure

- Breathlessness
- Pain
- Fatigue
- Anxiety
- Limitation in physical activity
- Nausea
- Ankle swelling
- Constipation
- Loss of appetite
- Sleeplessness
- Persistent cough
- Confusion
- Dizziness
- Depression
- Abdominal pain

2013 ACC/AHA HF guidelines

- “Additional areas of renewed interest are in stage D HF, palliative care, transition of care, and quality of care for HF.”
- Class IIb - Long-term, continuous intravenous inotropic support may be considered as palliative therapy for symptom control in select patients with stage D despite optimal GDMT and device therapy who are not eligible for either MCS or cardiac transplantation (Level of Evidence: B)
Stages in the development of HF and recommended therapy by stage.

Yancy C W et al. Circulation 2013;128:e240-e327

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What is Palliative Care?

“The goal of palliative care is to prevent and relieve suffering, and to support the best possible quality of life for patients and their families, regardless of their stage of disease or the need for other therapies”

Statement on Clinical Practice Guidelines for Quality Palliative Care, National Consensus Project for Quality Palliative Care 2009

- Improving QOL and supporting patients and their families who are living with serious and complex chronic illnesses in whom prognosis is uncertain or may be measured in years, independent of prognosis. Aims to relieve suffering by a multidisciplinary and holistic approach that addresses patients’ and caregivers’ physical, emotional, spiritual and logistical needs

Adler, Goldfinger et al. 2009
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


For Hospice Enrollment:

- 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
Hospice vs Palliative (VNA)

<table>
<thead>
<tr>
<th></th>
<th>Hospice</th>
<th>Palliative VNA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis</td>
<td>Terminal</td>
<td>Terminal or life-threatening</td>
</tr>
<tr>
<td>Prognosis</td>
<td>&lt; 6 months</td>
<td>Any</td>
</tr>
<tr>
<td>Goals of Rx</td>
<td>Solely Palliative</td>
<td>Any Goal</td>
</tr>
<tr>
<td></td>
<td>Not Curative or</td>
<td></td>
</tr>
<tr>
<td></td>
<td>restorative</td>
<td></td>
</tr>
<tr>
<td>Homebound</td>
<td>No</td>
<td>Yes, for Palliative VNA</td>
</tr>
</tbody>
</table>

HF-Specific Aspects of Palliative and End of Life Care

- Assurance of access to evidence-based disease-modifying interventions
  - Fluid management
- Symptom Management
  - Psychosocial distress
- Integration Advanced Therapies
  - Devices: Pacemakers, LVADS, ICDs
  - Procedures: TAVR, Cardiac surgery
  - Deactivation of Device-therapy
- Assistance with clinical decision making
  - Goal based decisions
  - Understanding of prognosis
  - Who is best suited for hospice
- Advanced Care Planning: Disease-specific
  - “Preparedness Plan”
  - Preferences about end of life care
- Caregiver support
- Assessment for frailty and dementia

Why Palliative Care?

- Better symptom management
- Lower levels of Medicare spending
- Improved mortality when applied early
- Higher use of hospice care
- Data shows that without:
  - More ICU and ED usage
  - Less Advance directives
  - More time in hospital despite wishes to contrary in their last yr
  - Decreased satisfaction
  - Increased number of facility transitions at EOL

Advance Care Planning

- Goals, Values, Hopes, Worries
- Patient/family time need to process information
- Process not a proclamation
- Start the Conversation….. And continue it….
- Disease specific plan
- Getting information on the types of life-sustaining treatments
- Deciding what types of treatment you would or would not want
- Benefits vs. Burdens
- Shared Decision Making
  - Role of palliative care with LVADs – initiation or discontinuing
Advanced Care Planning

- Mixed reviews about living wills and advance directives
  - Limited help in situation short of “terminally ill”
  - Difficult to predict treatment preferences in the future

- Strong evidence to support benefit of “in advance” end of life discussions
  - Hoping for the best but preparing for the worst

- Redefining the “planning” in advanced care planning: process more than a decision
  - Think about types of health care decisions in the future
  - Identify HCP
  - Conversation with HCP regarding values
  - Focus on goals of treatments: acceptable and unacceptable outcomes

Sudore RL. Redefining the "planning" in advanced care planning: preparing for end-of-life decision making. Annals of internal medicine. 2010

Trajectory of Heart Failure

- Transition to Advanced Heart Failure:
  - Oral therapies failing
  - A time for many major decisions
  - Consider MCS and/or transplantation, if eligible
  - Consider inserion of care plan to one dominated by a palliative approach, which may involve formal hospice

Late Referral to Palliative Care Does Not Allow Full Range of Services

- 2006-2011 132 HF pts with Palliative care consults
- Retrospective application of Seattle HF Model predicted 2.8 yr life expectancy but in fact median survival 21 days
- Most common reason for referral – GOC
- But only 10% of total HF population referred
  - Better referral mechanism needed
- Earlier referral include nonhospice benefits: advanced care planning, effective communication, treatment decision making.


Purpose

- To inform efforts aimed at integrating palliative care earlier in the HF trajectory we surveyed PCPs to inquire what HF- palliative care support and education they desired.
Methods

- A 20 item needs assessment was distributed using survey monkey to PCPs affiliated with an academic medical center via email by the Director of Palliative Care.
- Approved by the IRB

Subjects

- Of the 106 primary care physicians, nurse practitioners and physician assistants to receive the survey, 45 responded (42% response rate).
- Three (7%) of the providers had formal hospice training and 62% had continuing education about palliative care in the last 2 years.
### Subjects

<table>
<thead>
<tr>
<th>Role</th>
<th>Response Percent</th>
<th>Response Count</th>
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<tbody>
<tr>
<td>Family medicine physician</td>
<td>42.2%</td>
<td>19</td>
</tr>
<tr>
<td>Internal medicine physician</td>
<td>42.2%</td>
<td>19</td>
</tr>
<tr>
<td>Physician assistant</td>
<td>2.2%</td>
<td>1</td>
</tr>
<tr>
<td>Nurse practitioner</td>
<td>11.1%</td>
<td>5</td>
</tr>
<tr>
<td>Other</td>
<td>2.2%</td>
<td>1</td>
</tr>
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### Question 12

12. Has one of your patients with heart failure received an inpatient palliative care consult?

<table>
<thead>
<tr>
<th>Response</th>
<th>Response Percent</th>
<th>Response Count</th>
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<tr>
<td>Yes</td>
<td>57.8%</td>
<td>26</td>
</tr>
<tr>
<td>No</td>
<td>13.3%</td>
<td>6</td>
</tr>
<tr>
<td>I don't know</td>
<td>28.8%</td>
<td>13</td>
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</table>
If you had a consult was it helpful?

- The majority (73% although 27% did not know if there was a consult) of PCPs who previously received a consult for their HF patient in the hospital were satisfied with the care.
- “Both myself and my patients found this very helpful, supportive, educational, not at all morbid”.

Top 5 Topics to Refer to Palliative Care

- Connecting patients and their families to palliative and end of life resources
- Prognostication
- Symptom management
- Advance care planning
- Shared decision making
Reasons most likely refer a patient with HF for an outpt palliative care

- Fluid management
- Bereavement support
- Psychosocial issues
- ICD/LVAD deactivation
- Address QOL
- Shared decision making
- Advance care planning
- Symptom mgt
- Prognostication
- Connecting EOL resources

Top 5 Topics for Knowledge and Skills

- Prognostication
- Symptom management
- Assessing and addressing quality of life
- Advance care planning
- Device management.
10. If your patient was admitted to the hospital with a heart failure exacerbation, would you want a palliative care consult arranged?

<table>
<thead>
<tr>
<th>Response</th>
<th>Percent</th>
<th>Count</th>
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<tr>
<td>Yes</td>
<td>35.6%</td>
<td>10</td>
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<td>No</td>
<td>2.2%</td>
<td>1</td>
</tr>
<tr>
<td>Maybe</td>
<td>62.2%</td>
<td>28</td>
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</table>

11. If your patient was admitted to the hospital with a new diagnosis of heart failure would you want a palliative care consult?

<table>
<thead>
<tr>
<th>Response</th>
<th>Percent</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>11.1%</td>
<td>5</td>
</tr>
<tr>
<td>No</td>
<td>42.2%</td>
<td>19</td>
</tr>
<tr>
<td>Maybe</td>
<td>46.7%</td>
<td>21</td>
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Maybe, if... 15
15. If there was an option to have an outpatient palliative care consult for your patients with heart failure would you utilize this service?

<table>
<thead>
<tr>
<th></th>
<th>Response</th>
<th>Percent</th>
<th>Count</th>
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<tbody>
<tr>
<td>Yes</td>
<td></td>
<td>66.7%</td>
<td>30</td>
</tr>
<tr>
<td>No</td>
<td></td>
<td>4.4%</td>
<td>2</td>
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<tr>
<td>Maybe</td>
<td></td>
<td>25.9%</td>
<td>13</td>
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</table>

16. If you would like Heart Failure Palliative Care Clinic support, would it be:

<table>
<thead>
<tr>
<th>Support Type</th>
<th>Response Percent</th>
<th>Response Count</th>
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<tbody>
<tr>
<td>Short-term/episodic support</td>
<td>78.6%</td>
<td>33</td>
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<tr>
<td>Long-term involvement support</td>
<td>66.7%</td>
<td>28</td>
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<tr>
<td>Post hospitalization support</td>
<td>57.1%</td>
<td>24</td>
</tr>
<tr>
<td>Other</td>
<td>7.1%</td>
<td>3</td>
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</table>
Interest in Palliative Care Ed

- Seventy-three percent of respondents desired palliative care education for themselves or staff
- 11% NO
- 16% MAYBE

19. Are you interested in HF-Palliative Care Education for yourself or staff?

<table>
<thead>
<tr>
<th>Response</th>
<th>Response Percent</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>73.3%</td>
<td>33</td>
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<tr>
<td>No</td>
<td>11.1%</td>
<td>5</td>
</tr>
<tr>
<td>Maybe</td>
<td>15.6%</td>
<td>7</td>
</tr>
</tbody>
</table>
Our Current HF Palliative Care Model

- Inpatient consult service
- Heart Failure clinic – advance care planning, symptom management

Next Steps in Development

- Consider a series of visits for "Heart Failure HF: Preparedness" that included 3 structured visits with a clinician expert in both heart failure and palliative care addressing medication/fluid management, symptom management, caregiver support and advance care planning
- Marketing?
Conclusion

- Primary care desires additional palliative care knowledge especially about prognostication and symptom management and prefer online programs and grand rounds as the educational format.
- Primary Care Practitioners were satisfied with previous hospital HF palliative care consults but would not order a consult unless their patient was nearing the end of their life.
- Even though PCPs desire outpatient HF palliative care support, difficulty prognosticating and seeing palliative care as end-of-life care may limit timely referrals or implementation of advance care planning.
- Patient with advanced heart disease face unique challenges as they near the end of their lives:
  - Ambiguous prognosis
  - Complex symptomology
  - Multiple and complicated treatment options Palliative care is concurrent with restorative care
- More research is needed to determine at one point in the illness trajectory is the ideal time to refer to palliative care.