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Palliative Care Consultations for Heart Failure Patients: How Many, When, and Why?

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Abstract

Background—In preparation for development of a palliative care intervention for patients with heart failure (HF) and their caregivers, we aimed to characterize the HF population receiving palliative care consultations (PCCs).

Methods—Reviewing charts from January 2006 to April 2011, we analyzed HF patient data including demographic and clinical characteristics, Seattle Heart Failure scores, and PCCs. Using Atlas qualitative software, we conducted a content analysis of PCC notes in order to characterize palliative care assessment and treatment recommendations.

Results—There were 132 HF patients with PCCs, of which 37% were New York Heart Association (NYHA) Class III and 50% were Class IV. Retrospectively computed Seattle Heart Failure scores predicted 1-year mortality at 29% [IQR 19,45] and median life expectancy of 2.8 years [IQR1.6,4.2] years. Of the 132 HF patients, 115 (87%) had died by the time of the audit. In that cohort the actual median time from PCC to death was 21 [3, 125] days. Reasons documented for PCCs included: goals of care (80%), decision-making (24%), hospice referral/discussion (24%), and symptom management (8%).

Conclusions—Despite recommendations, PCCs are not being initiated until the last month of life. Current PCC referral mechanisms are inadequate for integrating the full range of palliative care services.

Keywords

Palliative Care; Consultation; Advanced Heart Failure

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Introduction

Almost 6 million Americans, most over age 65, carry a diagnosis of heart failure (HF).¹ Despite treatment advances, 50% of these HF patients will die within 5 years.¹ Increasing age is a prime risk factor associated with the greatest morbidity and mortality.^{2–5} Before death, individuals with HF will experience multiple hospitalizations⁶ and personal and economic costs of unrelieved physical and emotional suffering.^{7–13} Despite the challenges of long term symptom management, social and psychological distress, and quality of life when cure is not possible, there has been little progress in increasing HF patients' access to palliative care services.^{12,14–17} Prior to death, only 19% of Medicare-aged HF patients accessed palliative services (via the Medicare hospice benefit), compared with more than half of advanced cancer patients¹⁸, resulting in claims that palliative care integration in HF is two decades behind cancer.¹⁹ Barriers to the timely referral of HF patients to palliative care provider training in palliative care principles,¹⁴ delayed referral until all HF therapies have been exhausted,¹⁴ and lack of shared decision-making/advance care planning.²¹

The high physical and psychological burden of advanced HF and chance for sudden death underscores the importance of early initiation of palliative care services in order to optimize symptom management, healthcare team communication, advanced care planning, and identification of treatment goals consistent with patient values and preferences.^{22–24} Thus, the American Heart Association (AHA)²⁵ and other professional entities^{11,16,17,26–31} recommend a model of care consisting of palliative care concurrent with standard HF care. Yet despite these recommendations, many clinicians caring for persons with HF have been reluctant to address prognosis and goals of care and have struggled to recognize the "right time" to introduce palliative care referral is optimally timed puts HF patients and their families at great risk of not having access to supportive palliative care services until very late in the disease trajectory or not at all.^{24,32}

Over the past year, an interdisciplinary HF-Palliative Care Study Group met weekly to examine current HF care and practices and to develop and pilot test an early intervention palliative care model³³ that could be added to standard HF care. The purpose of this paper is to describe the results of a retrospective chart audit study of the cohort of patients who had experienced at least one admission between January 2006 and April 2011 with a primary admission diagnosis of HF and who had received a palliative care consultation (PCC). The Dartmouth College institutional review board exempted this study from review given its quality improvement and pre-clinical trial focus.

Brief Overview of the Heart Failure and Cardiomyopathy Program

Dartmouth-Hitchcock Medical Center (DHMC) has a long history of cardiac research, quality improvement, and clinical excellence. DHMC is a founding member of The Northern New England Cardiovascular Disease Study Group (NNECDSG) a regional voluntary consortium created in 1987 to exchange information and to conduct quality improvement studies related to geographic variation and treatment of heart disease in Maine, New Hampshire and Vermont.^{34,35} In 2004, the DHMC Heart Failure and Cardiomyopathy

(HFC) Program was established to serve the more than 1,000 Northern New England patients who are annually diagnosed with the most advanced heart disease. The HFC team includes physicians, nurse practitioners and care managers, a nutritionist, and rehabilitation specialists. Based on the chronic disease management model,^{36,37} the HFC provides streamlined coordination of care, patient education, enhanced access to the HF medical staff, follow-up appointments, and support groups.

Brief Overview of Palliative Care Consultation (PCC) Service

Providing inpatient, outpatient, and phone-based home care, DHMC's PCC service was initiated in 2003 following a cancer-focused, outpatient palliative care demonstration project^{38,39} conducted by DHMC's still active Palliative Care Research Team comprised of a PI (MB), research coordinators, nurse interventionists, and biostatisticians. The PCC Service consists of an interdisciplinary team of board-certified palliative medicine physicians, physician fellows in training, nurse practitioners, social workers, chaplains, registered nurses, volunteers, and administrative staff. PCCs are performed in the inpatient or outpatient setting and are requested by an attending physician for symptom management, establishing goals of care, and assistance with medical decision-making. A board-certified palliative medicine physician or nurse practitioner reviews the patient's electronic medical record, meets with and evaluates the patient and available family, and if appropriate, conducts family meetings. The standardized initial consultation⁴⁰ is documented in a templated note in the electronic health record. Based on specific needs, patients and their families are then followed by medical, psychosocial, spiritual, healing arts, and volunteer palliative care team members. All patients are presented and reviewed during daily interdisciplinary team meetings. Annually, the service performs approximately 860 inpatient (2,600 visits) and 270 outpatient (1,233 visits) consultations. Targeted expansion beyond cancer to all diseases began in 2003.

Methods

We conducted a retrospective, multi-method chart audit of patients who experienced at least one admission between January 2006 and April 2011 for a primary diagnosis of HF (ICD-9 codes 428.0 - 428.99) by reviewing electronic health records and administrative data. Of this initial cohort, we assessed palliative care utilization. Of the subset who received a PCC, we evaluated the reasons for and context of the PCC.

Data Collection

Demographic and clinical data were extracted from the electronic health record of the PCC cohort by 4 members of the study team (MM, KT, AR, LJ). Patient data collected included: age, gender, marital status, hospital length of stay, primary medical service, number of readmissions, cardiac diagnostic tests, laboratory values, medications, cardiac device use, and vital status (as of 1/12/12). Clinical, medication, and laboratory data, were entered into the web-based Seattle Heart Failure (SHF) prognostic score calculator (http://depts.washington.edu/shfm/app.php) and survival and mortality data was calculated for each patient.

The initial palliative care consultation note for each patient was identified in the electronic record, printed, and de-identified. Qualitative data regarding reasons for referral for palliative consultation, parameters assessed and recommendations for treatment were identified in the initial palliative care consultation note. Palliative care consultation evaluation and management activities were categorized by applying a modified coding schema developed by Bekelman and colleagues.⁴¹ The HF-Palliative Care Study Group senior HF cardiologist (AK) and the palliative care expert (MB) adjudicated HF or palliative care clinical issues that arose during chart reviews.

Data Analysis

Proportions, interquartile ranges (IQR), means and standard deviations were calculated on continuous and categorical variables using SAS (v.9.2, Cary, NC). Non-normal distributions are reported as medians and interquartile ranges.

Printed consultation notes were entered into Atlas.ti Qualitative Software (V.6.2 Berlin) for qualitative content analysis. PCC notes were then coded by members of the study team (LJ, MM, KT, AK). The principle investigator (MB), an experienced qualitative researcher, trained and evaluated inter-rater reliability among coders by duplicate abstraction of each coders first 5 notes. The PI and coders then met as a group and compared the independently coded segments for agreement. During this process, code definitions were clarified and, when necessary, coding disagreements were resolved by discussion until consensus was reached for all ratings.

Results

Demographics

Between January 1, 2006 and April 1, 2011 we identified 1,763 HF admissions representing 1,320 unique patients. Most (n=975) were age 65 or older with a mean age of 74 years. Of the 1,320 HF patients, 135 (10%) were identified as having had a PCC, representing approximately 27 HF PCCs each year. However 3 of these 135 records were eliminated due to coding errors of the primary diagnosis. In the resulting subset of 132 HF patients; 115 patients received their initial PCC as inpatients and 17 as outpatients. The 132 HF patient cohort received 516 total palliative care visits.

Table 1 shows the characteristics of the HF cohort who received a PCC. The median age at the time of consultation was 76. Most patients were Caucasian reflecting the geographic racial profile in the catchment area. Just over half of the patients were male (53%; n=70) and married (56%; n=70); 68% of these patients had completed advance directives. Cardiology was the most common referring service (62%; n=82), followed by Hospitalist (18%; n=24) and Internal Medicine (14%; n=19) services. Of the 115 patients seen as inpatients the majority were discharged home with visiting nurse support (30%; n=35) or to a skilled nursing facility (21%; n=24). Fifteen percent (n=17) of patients were discharged home with hospice and 9% (n=10) died in the hospital.

Disease and Treatment Status

Of the HF patients receiving PCCs, 37% (n=49) were NYHA Stage III and 50% (n=66) were NYHA Class IV (Table 1). The median ejection fraction was 40% and 23% (n=30) of the cohort had an advanced therapy device such as a biventricular pacemaker, implanted cardiac defibrillator (ICD) or a combined device. Table 2 divides the cohort by 4 levels of ejection fraction and for each level, indicates the number of patients who had an implanted cardiac device. Less than a quarter of the sample (23%) had an EF below 20%-- the value that is consistent with HF Medicare hospice eligibility criteria.⁴²

Table 3 provides the percentage of the cohort that was taking cardiac medications, diuretics, and the median and interquartile range [IQR] for laboratory values. At the time of the consultation, most patients were being treated with beta blockers and half were receiving statins. Sixty three percent were receiving a diuretic with furosemide being the most common. Median lab values for the sample closest to the time of the consultation are listed in Table 3. The labs shown are those that were collected to estimate the SHF scores. Median levels of hemoglobin, lymphocyte percent, and cholesterol were on the lower side of normal, uric acid was slightly elevated, and sodium was within normal limits.

Seattle Heart Failure Model (SHFM) Predicted v. Observed Mortality

Age, gender, ischemic etiology, NYHA classification, ejection fraction, systolic blood pressure, diuretic, statin and, allopurinol use, hemoglobin, lymphocyte count, uric acid, sodium, and cholesterol ⁴³ were used to calculate the Seattle Heart Failure Model (SHFM) mortality and survival estimates for each patient. Table 4 details the virtually identical SHFM estimated 1-year survival and mortality and calculated life expectancy for the total HF PCC cohort and the 115 decedents. At the time of the initial PCC, the SHFM predicted 1 year median survival was 72% and the calculated median life expectancy was 2.8 years. Actual median survival time from PCC until till death was 21 days.

Length of time from Index Hospitalization until PCC and Readmissions

Figure 1 illustrates that the length of time (in days) between the index hospitalization and the palliative care consultation was 110 days. There was a median of 1 hospitalization following PCC (range 0–15) (data not shown).

Documented PCC Evaluation and Treatment Recommendations

The data source for Tables 5 and 6 were the coded PCC consultation notes.

Reason for referral—Table 5 lists the reason for referral as documented in the PCCs. As described previously most PCCs (n=115) were performed when patients were in-hospital. The primary reasons included goals of care (80%), decision making support (24%), hospice referral/discussion (24%), and symptom management (18%). Relatively few consults were placed for introduction to palliative care (17%), advanced care planning (16%), and coping with serious illness (14%). Only 2 consultations were requested to have a family meeting.

Palliative Care Evaluation—Table 6 shows that social support (partner status, caregiver/family support, living arrangements), emotional well-being, advanced directive/code status

and goals of care were evaluated in more than 80% of the consultation notes. Areas and concerns evaluated less frequently by PCCs were substance use, and financial, cultural and educational background. Explicit documentation of symptoms that were evaluated most frequently included cognitive/mental status, mood, breathing, and general pain. Symptoms evaluated 20% or less of the time were sleep, anorexia, chest pain, constipation/diarrhea, and dry mouth.

Treatment and Symptom Recommendations—Table 6 also lists PCC general and symptom-specific treatment recommendations. In nearly half of the consultations treatment recommendations were made for additional supportive counseling, initiating medications, and family or provider care coordination. Family meetings were recommended in 39% of consults. Equal proportions of recommendations (19%) were made related to cardiac and non-cardiac "advanced therapeutics". Recommendations related to advanced cardiac therapeutics might include discussions about continuing or discontinuing cardiac pacemakers and/or implanted defibrillators. Recommendations about non-cardiac advanced therapies related to treatments such as dialysis, chemotherapy, etc. Treatment recommendations for specific symptoms most frequently included breathlessness, general pain, anxiety, and depression. Less frequently were recommendations made for chest pain, nausea/vomiting, or diarrhea.

Advance Care Planning Interventions—Table 6 also identifies specific interventions related to advance care planning concerns such as hospice referral, weighing and considering goals of care, prognosis, and discussion of the expected illness trajectory. Recommendations to identify a surrogate were made in only 13% of cases.

Discussion

In preparation for a randomized clinical trial of early concurrent palliative care in older adults with heart failure and their families compared to usual heart failure care, we sought to examine and describe the baseline utilization of palliative care and to characterize the HF patient cohort who was currently receiving PCCs. We conducted a 5-year retrospective chart audit of patients at our tertiary academic medical center who had experienced at least one heart failure admission in order to identify HF patients with a potentially advanced stage of disease. Our aim was to better understand what proportion of HF patients were currently receiving PCCs, when in the disease trajectory they were getting them, and for what reasons.

We identified a cohort of 132 HF patients (10% of the total population admitted with a HF diagnosis) who received a PCC during the 5-year study period. The median actual survival time of 21 days of this cohort was remarkably short compared to the median predicted length of survival estimated by the SHFM. This suggests that this cohort was not identified for by their clinician for PCC until they were acutely and seriously medically ill and in their later stages of dying. While palliative care consultation can provide important advice related to EOL care planning, these patients were clearly not getting the advantage of the full range of services available from a mature palliative care service.⁴⁴ AHA recommendations^{45,46} and others^{33,44} support the value of earlier introduction of palliative care services in chronically-ill older adults. Our own team's experience in initiating early, concurrent

palliative care in the cancer population³³ has demonstrated that early concurrent PCC for patients who have at least a one year prognosis can result in improved quality of life, reduced symptom intensity, less depression and trends in improved survival compared to usual care. In the HF cohort the median time from an index HF admission to PCC was 110 days or little over 3 months. At that index admission there may have been triggers that could have identified opportunities for palliative referral well before a referral was actually made (e.g. multiple admissions, attempting multiple treatments over a period of several months, consideration of advanced cardiac diagnostics or treatments and overall clinical decline).

The challenge in HF is how to identify the cohort of HF patients who might benefit from the full range of palliative services earlier in the trajectory of advanced disease? While others have attempted to identify HF patients who are hospice eligible,⁴² our goal is to identify patients who could benefit sooner from other non-hospice palliative services such as advanced care planning and learning strategies for communication and treatment decision making.⁴⁷ We retrospectively calculated SHFM scores to determine whether this prognostic tool for survival/mortality might be feasible for early identification of HF patients who might benefit from palliative care services. Prognostic algorithms such as the SHFM have been widely promoted to aid practitioners in prognosticating heart failure patients' survival/mortality.⁴⁸ The SHFM was developed from the PRAISE Trial, an outpatient randomized trial of heart failure patients with systolic dysfunction.⁴³ Survival/mortality criterion estimates were accounted for by various clinical, functional, laboratory and intervention variables and this predictive regression model has been prospectively validated by comparing results to other published studies.

Performance of the SHFM in our study, however, was underwhelming but not completely unexpected given that the SHFM was developed for an ambulatory population.⁴³ In our cohort, at the time of the initial PCC the median SHFM predicted 1 year mortality was only 29% and the calculated median life expectancy was 2.8 years. However the actual median survival time from consultation until death was only 21 days indicating gross imprecision of the SHFM score estimates in a more seriously ill population. The finding is not without precedent: for example, James et al. ²⁹ retrospectively applied the SHFM at admission and discharge to a cohort of 214 HF patients to determine who might have benefited from a palliative care referral based on a predicted life expectancy 1.5 years. They concluded that 63% (n = 17) of the 27 "poor prognosis" patients would have been appropriately identified for PCC. Of particular note is that James et al. also found that half of the cohort of 104 patients had died and 82% of them had died in 1.5 years; however only 16% of the decedents were categorized in the 1.5 years of survival group. This highlights a huge discrepancy between predicted patient survival/mortality based on SHFM scores and actual survival/mortality. Hence, we have doubts in the utility of this prognostic tool to reliably identify HF patients early enough to benefit from the full range of palliative care services. This rather bleak assessment of both clinical judgment and prognostic tools in our study in identifying HF patients that might benefit from PCC, creates a great opportunity for development of models that might identify patients earlier.

In the inpatient setting, there may be potentially other useful needs-based predictive models that calculate dependence after discharge and likelihood of hospital readmission. Being able

to predict HF inpatients' risk for readmission may act as a more effective trigger for early palliative care involvement. Identifying patient characteristics which predict readmission, an area potentially able to be impacted by palliative care, and using a validated prediction tool to determine individual patients' risk for readmission can be used to stratify patients into high or low risk for readmission. Thus, patients at high risk for readmission may benefit more from palliative services compared to the patients in the low risk group. Ross et al.⁴⁹ published a comprehensive systematic review of studies which presented models designed to predict readmissions in patients with HF and studies that evaluated what patient characteristics were associated with readmission. In their review, Ross and colleagues found only one study that predicted heart failure readmissions. This study by Philbin et al.¹⁹ developed a 15 point score prediction model for HF readmission within one year using multivariate regression analysis. The risk model assigned a baseline score of 4 points, and added one additional point based on the presence of any of the following variables: African American race, Medicare or Medicaid as primary health insurance, ischemia heart disease, valvular heart disease, diabetes, kidney disease, chronic lung disease, idiopathic cardiomyopathy, heart surgery, telemetry use during the index admission, after discharge use of home health services. Ross et al.'s systematic review also identified over a hundred studies analyzing the association between all cause readmission and HF patient characteristics. Variables inconsistently associated with readmission included age, gender, diabetes, hypertension, left ventricular systolic function, NYHA class, creatinine, blood urea nitrogen, and sodium level. Characteristics that were more consistent included troponin and B-type natriuretic peptide.

Ability to predict heart failure admissions is of great interest to our team, not only because it might be a promising strategy to identify and recruit HF patients for an early palliative care intervention, but also because HF is the most common discharge diagnosis among Medicare patients⁵⁰ and these admissions can be costly due to the high acuity and associated comorbidities.² Aiming to significantly reduce all cause readmissions in the HF population represents a lofty but potentially achievable goal for an early palliative care intervention.

PCCs were requested most commonly to assist with establishing goals of care (80%; n=105; Table 5), a request which typically signals that a structured discussion is needed about the ineffectiveness of tried medical treatments and the need to adopt a philosophy of care that is based on patients values and preferences for care when disease focused treatments are no longer effective measures. Other common reasons to request PCC include decision making (24%; n=32) and hospice referral/discussion (24%; n=31). We were surprised at the relatively low rate of PCCs requested for symptom management (18%; n=24) given the high symptom burden that accompanies heart failure. Topics in palliative care typically addressed early in an illness were seen less frequently in this population, including introduction of palliative care services (17%; n=22), advanced care planning (16%; n=21), and coping with serious illness (14%; n=18).

The high frequency with which PCCs were requested to clarify patient goals, support decision making and assist with transitioning medical care to a comfort-oriented approach suggests that our referring physicians were well aware of the resource that palliative care provides relative to EOL decision-making. This is consistent with a recent poll of MDs that

demonstrated that their predominant experiences/impression with palliative care were around providing "comfort care at EOL"⁵¹; acceptance of palliative care in this situation is a positive trend. Even so, the finding that a mere 10% of the total HF population was referred for palliative care services, suggests that palliative care referral based solely on physicians' clinical judgment of prognoses and palliative care needs is currently suboptimal as a referral mechanism for an early palliative care intervention. Additionally, the median observed survival of 21 days in our patient group suggests that these discussions were taking place in the setting of late-stage illness, and as such these referral patterns reflected a tendency to be reactive to patient illness rather than working proactively. This is further supported by the relatively low frequency with which PCCs were requested for topics commonly addressed in early illness. To date there has been little research regarding the best timing and elements for palliative care for patients other than those with metastatic cancer or cancers with a high symptom burden.⁵² Our current pilot study in progress is attempting to sort out this question.

Limitations

This study had a number of limitations. Our study was a retrospective review of data available from chart audits; therefore there was very little information about the thought processes of the referring clinicians or the actual circumstances surrounding the identification of HF patients for PCC. The sample was homogenous in terms of ethnicity and race, reflecting the population in our catchment area. The calculation of the SHFM scores could be somewhat imprecise as it was based to a small degree on imputed data. Some values were missing or we used a value that was in close proximity to the date of the PCC, but this may have preceded the consult by months.

Clinical and Research Implications and Conclusions

Providing palliative care concurrent with standard HF care has been proposed as a model to reduce symptom burden, anxiety, and depression and to improve overall quality of life in those living with HF.^{16,25,32,53} The majority of evidence supporting the use of palliative care comes from the cancer literature, but many of the demonstrated benefits for cancer patients would likely apply to the heart failure population. Patients with HF have been shown to have higher burden of symptoms and depression and lower spiritual well-being than patients with metastatic cancer.⁵⁴ Multiple studies,⁵² including our own,³³ have demonstrated improvement in cancer patients symptoms and quality of life when palliative care is involved early; we see no obvious reason to suppose that such improvements are not possible in the HF population. In addition to decreasing the symptom burden, initiating advance care planning, can be valuable for patients with an unpredictable illness trajectory that is subject to unanticipated episodes of acute and life threatening decompensation.³ Additionally, with the increasing availability of advanced therapies for HF patients, thorough exploration of a patient's goals and preferences for medical care can help both patients and clinicians discern more efficiently and effectively the array of choices available.5,45,55,56

Page 10

Important clinical implications of our study include the importance of providing early palliative care so that patients have opportunities to prevent and mitigate symptoms, proactively improve their quality of life, and discuss advance care planning as their condition worsens. Similarly family benefits related to preparation and support would be able to be offered, which could have a significant impact on their overall mental and physical health and well-being.^{57,58}

From a research perspective there is clearly an important opportunity to fill a gap in how to best identify the needs and timing of providing palliative care to patients with HF. Palliative care approaches in this context must be adaptable to the episodic, unpredictable HF illness trajectory and appeal to patients who are not dying but desire to better manage their health and well-being.^{17,59} The majority of palliative care interventions have been developed with cancer populations and the trajectory of HF differs in duration and pattern. However there are many lessons from cancer that can be applied in terms of strategies for communication, decision-making, problem solving, symptom self-management, and holistic support. Bridging these approaches to the HF population is a key research agenda in the scientific and professional communities.

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References

- Roger VL, Go AS, et al. Writing Group Members. Executive Summary: Heart Disease and Stroke Statistics--2011 Update: A Report From the American Heart Association. Circulation. 2011 Feb 1; 123(4):459–463. 2011.
- Forman DE, Rich MW, Alexander KP, et al. Cardiac Care for Older Adults Time for a New Paradigm. Journal of the American College of Cardiology. 2011 May 3; 57((18)):1801–1810. [PubMed: 21527153]
- 3. Bekelman DB, Hutt E, Masoudi FA, Kutner JS, Rumsfeld JS. Defining the role of palliative care in older adults with heart failure. Int J Cardiol. 2008 Apr 10; 125(2):183–190. [PubMed: 18022710]
- 4. Buck HG, Riegel B. The impact of frailty on health related quality of life in heart failure. Eur J Cardiovasc Nurs. 2010 Jun 28.
- Waterworth S, Jorgensen D. It's not just about heart failure--voices of older people in transition to dependence and death. Health Soc Care Community. 2010 Mar; 18(2):199–207. [PubMed: 20039966]
- Unroe KT, Greiner MA, Hernandez AF, et al. Resource use in the last 6 months of life among medicare beneficiaries with heart failure, 2000–2007. Arch Intern Med. 2011 Feb 14; 171(3):196– 203. [PubMed: 20937916]
- Bekelman DB, Rumsfeld JS, Havranek EP, et al. Symptom burden, depression, and spiritual wellbeing: a comparison of heart failure and advanced cancer patients. J Gen Intern Med. 2009 May; 24(5):592–598. [PubMed: 19288160]

- Currow DC, Smith J, Davidson PM, Newton PJ, Agar MR, Abernethy AP. Do the trajectories of dyspnea differ in prevalence and intensity by diagnosis at the end of life? A consecutive cohort study. J Pain Symptom Manage. 2010 Apr; 39(4):680–690. [PubMed: 20413056]
- Goebel JR, Doering LV, Lorenz KA, Maliski SL, Nyamathi AM, Evangelista LS. Caring for special populations: total pain theory in advanced heart failure: applications to research and practice. Nurs Forum. 2009 Jul-Sep;44(3):175–185. [PubMed: 19691653]
- Goebel JR, Doering LV, Shugarman LR, et al. Heart failure: the hidden problem of pain. J Pain Symptom Manage. 2009 Nov; 38(5):698–707. [PubMed: 19733032]
- Goodlin SJ. Palliative care in congestive heart failure. J Am Coll Cardiol. 2009 Jul 28; 54(5):386– 396. [PubMed: 19628112]
- O'Leary N, Murphy NF, O'Loughlin C, Tiernan E, McDonald K. A comparative study of the palliative care needs of heart failure and cancer patients. Eur J Heart Fail. 2009 Apr; 11(4):406– 412. [PubMed: 19196753]
- Fang J, Mensah GA, Croft JB, Keenan NL. Heart failure-related hospitalization in the U.S., 1979 to 2004. J Am Coll Cardiol. 2008 Aug 5; 52(6):428–434. [PubMed: 18672162]
- Berry JI. Hospice and heart disease: missed opportunities. J Pain Palliat Care Pharmacother. 2010 Mar; 24(1):23–26. [PubMed: 20345196]
- Chattoo S, Atkin KM. Extending specialist palliative care to people with heart failure: semantic, historical and practical limitations to policy guidelines. Soc Sci Med. 2009 Jul; 69(2):147–153. [PubMed: 19297064]
- Howlett JG. Palliative care in heart failure: addressing the largest care gap. Curr Opin Cardiol. 2011 Mar; 26(2):144–148. [PubMed: 21252651]
- Hupcey JE, Penrod J, Fogg J. Heart failure and palliative care: implications in practice. J Palliat Med. 2009 Jun; 12(6):531–536. [PubMed: 19508139]
- Bakitas M, Bishop MF, Caron P, Stephens L. Developing successful models of cancer palliative care services. Semin Oncol Nurs. 2010 Nov; 26(4):266–284. [PubMed: 20971407]
- Philbin EF, DiSalvo TG. Prediction of hospital readmission for heart failure: development of a simple risk score based on administrative data. J Am Coll Cardiol. 1999 May; 33(6):1560–1566. [PubMed: 10334424]
- 20. Konstam MA, Greenberg B. Transforming health care through the medical home: the example of heart failure. J Card Fail. 2009 Nov; 15(9):736–738. [PubMed: 19879458]
- Waterworth S, Gott M. Decision making among older people with advanced heart failure as they transition to dependency and death. Curr Opin Support Palliat Care. 2010 Dec; 4(4):238–242. [PubMed: 20966758]
- 22. Goldstein N, Bradley E, Zeidman J, Mehta D, Morrison RS. Barriers to conversations about deactivation of implantable defibrillators in seriously ill patients: results of a nationwide survey comparing cardiology specialists to primary care physicians. J Am Coll Cardiol. 2009 Jul 21; 54(4):371–373. [PubMed: 19608038]
- Goldstein N, Carlson M, Livote E, Kutner JS. Brief communication: Management of implantable cardioverter-defibrillators in hospice: A nationwide survey. Ann Intern Med. 2010 Mar 2; 152(5): 296–299. [PubMed: 20194235]
- Goldstein NE, Lynn J. Trajectory of end-stage heart failure: the influence of technology and implications for policy change. Perspect Biol Med. 2006 Winter;49(1):10–18. [PubMed: 16489273]
- 25. Hunt SA, Abraham WT, Chin MH, et al. 2009 focused update incorporated into the ACC/AHA 2005 Guidelines for the Diagnosis and Management of Heart Failure in Adults: a report of the American College of Cardiology Foundation/American Heart Association Task Force on Practice Guidelines: developed in collaboration with the International Society for Heart and Lung Transplantation. Circulation. 2009 Apr 14; 119((14)):e391–e479. [PubMed: 19324966]
- Lewis EF. End of life care in advanced heart failure. Curr Treat Options Cardiovasc Med. 2011 Feb; 13(1):79–89. [PubMed: 21221915]
- 27. Fitzsimons D, Strachan PH. Overcoming the challenges of conducting research with people who have advanced heart failure and palliative care needs. Eur J Cardiovasc Nurs. 2011 Feb 15.

- Johnson MJ, Booth S. Palliative and end-of-life care for patients with chronic heart failure and chronic lung disease. Clin Med. 2010 Jun; 10(3):286–289. [PubMed: 20726465]
- James T, Offer M, Wilson M, Delyea A, Johnson D. Increasing Palliative Consults for Heart Failure Inpatients Using the Seattle Heart Failure Model. J Hosp Palliat Nurs. 2010 Sep-Oct;12(5): 273–281.
- 30. Jaarsma T, Beattie JM, Ryder M, et al. Palliative care in heart failure: a position statement from the palliative care workshop of the Heart Failure Association of the European Society of Cardiology. Eur J Heart Fail. 2009 May; 11(5):433–443. [PubMed: 19386813]
- Garin O, Ferrer M, Pont A, et al. Disease-specific health-related quality of life questionnaires for heart failure: a systematic review with meta-analyses. Qual Life Res. 2009 Feb; 18(1):71–85. [PubMed: 19052916]
- Davidson PM, Macdonald PS, Newton PJ, Currow DC. End stage heart failure patients palliative care in general practice. Aust Fam Physician. 2010 Dec; 39((12)):916–920. [PubMed: 21301671]
- Bakitas M, Lyons K, Hegel M, et al. Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: The Project ENABLE II Randomized Controlled Trial. JAMA. 2009; 302(7):741–749. [PubMed: 19690306]
- Haskins AE, Siewers AE, Malenka DJ, Wennberg DE, Lucas FL. Characteristics of new cardiac surgery programs in the United States: mitigating the learning curve. Am Heart J. 2010 May; 159(5):919–925. [PubMed: 20435206]
- Malenka DJ, Kaplan AV, Lucas FL, Sharp SM, Skinner JS. Outcomes following coronary stenting in the era of bare-metal vs the era of drug-eluting stents. JAMA. 2008 Jun 25; 299((24)):2868– 2876. [PubMed: 18577731]
- 36. Wagner E. Chronic disease management: what will it take to improve care for chronic illness? Effective Clinical Practice. 1998; 1:2–4. [PubMed: 10345255]
- Wagner EH, Austin BT, C D, Hindmarsh M, Schaefer J, Bonomi A. Improving chronic illness care: translating evidence into action. Health Aff. 2001; 20(6):64–78.
- Bakitas M, Ahles TA, Skalla K, et al. Proxy perspectives regarding end-of-life care for persons with cancer. Cancer. 2008 Apr 15; 112(8):1854–1861. [PubMed: 18306393]
- Bakitas M, Stevens M, Ahles T, et al. Project ENABLE: A palliative care demonstration project for advanced cancer patients in three settings. J Palliat Med. 2004; 7(2):363–372. [PubMed: 15130218]
- Jacobsen J, Jackson V, Dahlin C, et al. Components of Early Outpatient Palliative Care Consultation in Patients with Metastatic Nonsmall Cell Lung Cancer. Journal of Palliative Medicine. 2011 Apr; 14(4):459–464. [PubMed: 21417739]
- Bekelman DB, Nowels CT, Allen LA, Shakar S, Kutner JS, Matlock DD. Outpatient palliative care for chronic heart failure: a case series. J Palliat Med. 2011 Jul; 14(7):815–821. [PubMed: 21554021]
- 42. Huynh BC, Rovner A, Rich MW. Identification of older patients with heart failure who may be candidates for hospice care: development of a simple four-item risk score. J Am Geriatr Soc. 2008 Jun; 56(6):1111–1115. [PubMed: 18482294]
- 43. Levy WC, Mozaffarian D, Linker DT, et al. The Seattle Heart Failure Model: prediction of survival in heart failure. Circulation. 2006 Mar 21; 113((11)):1424–1433. [PubMed: 16534009]
- 44. Adler ED, Goldfinger JZ, Kalman J, Park ME, Meier DE. Palliative care in the treatment of advanced heart failure. Circulation. 2009 Dec 22; 120((25)):2597–2606. [PubMed: 20026792]
- 45. Allen LA, Stevenson LW, Grady KL, et al. Decision Making in Advanced Heart Failure. Circulation. 2012 Apr 17; 125((15)):1928–1952. 2012. [PubMed: 22392529]
- 46. Jessup M, Abraham WT, Casey DE, et al. 2009 Focused Update: ACCF/AHA Guidelines for the Diagnosis and Management of Heart Failure in Adults: A Report of the American College of Cardiology Foundation/American Heart Association Task Force on Practice Guidelines: Developed in Collaboration With the International Society for Heart and Lung Transplantation. Circulation. 2009 Apr 14; 119((14)):1977–2016. 2009. [PubMed: 19324967]
- Bakitas M, Kryworuchko J, Matlock DD, Volandes AE. Palliative medicine and decision science: the critical need for a shared agenda to foster informed patient choice in serious illness. Journal of Palliative Medicine. 2011 Oct; 14((10)):1109–1116. [PubMed: 21895453]

- Brannstrom M, Boman K. A new model for integrated heart failure and palliative advanced homecare - rationale and design of a prospective randomized study. European Journal of Cardiovascular Nursing. 2012 Forthcoming.
- Ross JS, Mulvey GK, Stauffer B, et al. Statistical models and patient predictors of readmission for heart failure - A systematic review. Archives of Internal Medicine. 2008 Jul 14; 168((13)):1371– 1386. [PubMed: 18625917]
- Rich MW, Beckham V, Wittenberg C, Leven CL, Freedland KE, Carney RM. A multidisciplinary intervention to prevent the readmission of elderly patients with congestive heart failure. N Engl J Med. 1995 Nov 2; 333((18)):1190–1195. [PubMed: 7565975]
- 51. Center to Advance Palliative Care. 2011 Public Opinion Research on Palliative Care: A Report Based on Research by Public Opinion Strategies. New York: Center to Advance Palliative Care and American Cancer Society Action Network; 2011.
- 52. Smith TJ, Temin S, Alesi ER, et al. American Society of Clinical Oncology Provisional Clinical Opinion: The Integration of Palliative Care into Standard Oncology Care. Journal of Clinical Oncology. 2012 Feb 6.
- 53. National Consensus Project. Clinical Practice Guidelines for Quality Palliative Care. Second Edition. Brooklyn, NY: National Consensus Project for Quality Palliative Care; 2009.
- Bekelman DB, Havranek EP. Palliative care for patients with acute decompensated heart failure: an underused service? Nat Clin Pract Cardiovasc Med. 2008 May; 5(5):250–251. [PubMed: 18283302]
- 55. Goldstein NE, Mehta D, Teitelbaum E, Bradley EH, Morrison RS. "It's like crossing a bridge" complexities preventing physicians from discussing deactivation of implantable defibrillators at the end of life. J Gen Intern Med. 2008 Jan; 23(Suppl 1):2–6. [PubMed: 18095036]
- 56. Pettit SJ, Browne S, Hogg KJ, et al. ICDs in end-stage heart failure. BMJ Supportive & Palliative Care. 2012 Jun 1; 2(2):94–97. 2012.
- Wright AA, Zhang B, Ray A, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. JAMA. 2008 Oct 8; 300((14)):1665–1673. [PubMed: 18840840]
- Hebert RS, Prigerson HG, Schulz R, Arnold RM. Preparing caregivers for the death of a loved one: a theoretical framework and suggestions for future research. Journal of Palliative Medicine. 2006 Oct; 9(5):1164–1171. [PubMed: 17040154]
- 59. Hupcey JE, Penrod J, Fenstermacher K. Review article: a model of palliative care for heart failure. Am J Hosp Palliat Care. 2009 Oct-Nov;26(5):399–404. [PubMed: 19357374]

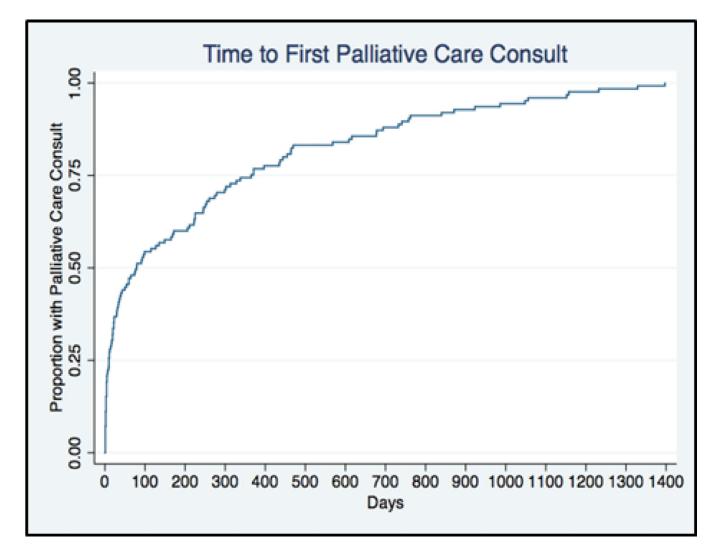


Figure 1.

Time from Index Heart Failure Admission to First Palliative Care consultation

Demographics and Clinical Parameters of Heart Failure Patients with Palliative Care Consults (N=132)

	Median [IQR] or No. (%)
Age	76 [67, 82]
Male	70 (53)
Marital Status	
Married	74 (56)
Widowed	35 (27)
Divorced	14 (11)
Single	7 (5)
Separated	2 (2)
Race	
White	129 (98)
Black	1 (1)
Asian Pacific Islander	1 (1)
Native American	1 (1)
Systolic Blood Pressure	110 [94, 122]
Weight kg ^a	77 [62, 90]
Advanced Directive at First Consult	90 (68)
Ejection Fraction ^b	40 [25, 64]
Patients with Cardiac Devices	30 (23)
NYHA Class	
I	9 (7)
П	8 (6)
III	49 (37)
IV	66 (50)
Referring Department	
Cardiology	82 (62)
Hospital Medicine	24 (18)
Internal Medicine	19 (14)
Hematology/Oncology	4 (3)
Thoracic Surgery	1 (1)
Anesthesiology	1 (1)
Cardiac Surgery	1 (1)
Discharged to ^C	
Home with Visiting Nurse	35 (30)
Skilled Nursing Facility	24 (21)
Home	20 (17)
Home with Hospice	17 (15)
Deceased	10 (9)
Swing Bed	5 (4)

	Median [IQR] or No. (%)
Rehabilitation Center	1 (1)
Transferred to Federal Hospital	1 (1)

a_{n=131}

^b_{n=130}

 $^{c}n=115$; only patients seen as inpatients have discharge data

Detailed Ejection Fraction and Device Data

N=130		Patients with Devices (n=30)
Median Ejection Fraction	No. (%)	No. (%)
50%	49 (38)	1 (.02)
36–49%	17 (13)	4 (24)
21-35%	34 (26)	8 (24)
20%	30 (23)	17 (13)

Medications, Diuretics, Laboratory Data and Device Use

	N=132 No. (%)
Medications	
ACE-I ^a	34 (26)
ARB ^b	21 (16)
Aldosterone Blocker	13 (10)
Beta-blocker	91 (69)
Statin	67 (51)
Allopurinol	13 (10)
Diuretics	
Furosemide	66 (50)
Bumentanide	3 (2)
Torsemide	9 (7)
Metolazone	5 (4)
Hydrochlorothiazide	1 (1)
Lab Data	Median [IQR]
Hemoglobin	10.9 [9.7, 12.4]
Lymphocyte %	11.7 [6.9, 17.0]
Uric Acid	8.6 [6.6, 8.6]
Total Cholesterol	133.5 [104.8, 150.3]
Sodium	137 [133.0, 141.0]

 a ACE-I=angiotensin-converting-enzyme inhibitor

^bARB=angiotensin receptor blocker

IRQ=interquartile range

Seattle Heart Failure Model (SHFM) Predicted and Observed Mortality and Survival

Median [IQR]		
	SHFM Predicted ^a	Observed ^b
One Year Mortality (%)	29 [19, 45]	115 (87%)
Mean Life Expectancy (years)	2.8 [1.6, 4.2]	0.06 [0.01, 0.34]
Mean Life Expectancy (days)	1022 [584, 1533]	21 [3, 125]

 $a_{n=129}$ Seattle Heart Failure scores not calculated for 3 patients due to missing data

 $b_{n=115}$ deaths- Vital status known as of January 12, 2012.

Reasons for Consult

	N=132 No. (%)
Goals of Care	105 (80)
Decision-making	32 (24)
Hospice Referral/Discussion	31 (24)
Symptom Management	24 (18)
Introduction of Palliative Care Services	22 (17)
Advanced Care Planning	21 (16)
Coping with Serious Illness	18 (14)
Discharge and Palliative Care Planning	12 (9)
Supportive Counseling	8 (6)
Family Meeting	5 (4)
Withdrawal of Life-prolonging Interventions	3 (2)

Note: Percentages add to over 100% due to multiple reasons listed per consult.

Areas of Evaluation and Management Present in Consultation Notes

	N=132 No. (%) in which the code appeared at least once
Areas Evaluated in Initial Consultation	
Marital/Partner Status	122 (92)
Spirituality/Emotional Well-being	118 (89)
Advanced Directive & Code Status	114 (86)
Caregiver/Family Support/Children	113 (86)
Goals of Care	112 (85)
Living Arrangements	110 (83)
Surrogate Identified	88 (67)
Work History	82 (62)
Functional Status	78 (59)
Decisional Capacity	63 (48)
Prognosis Understanding	59 (45)
Hospice	54 (41)
Substance Abuse	29 (22)
Financial	28 (21)
Cultural Background	28 (21)
Education	10 (8)
Symptoms Evaluated in Initial Consultation	
Cognitive/Mental Status	94 (71)
Mood	89 (67)
Breathlessness	87 (66)
General Pain	87 (66)
Fatigue	60 (45)
Weight Loss/Dietary Concerns	44 (33)
Grief & Bereavement	38 (29)
Nausea/Vomiting	37 (28)
Sleep Problem	27 (20)
Anorexia	26 (20)
Chest Pain	23 (17)
Constipation	22 (17)
Diarrhea	20 (15)
Dry Mouth	16 (12)
Treatment Recommendation	
Counseling: Supportive, Psychodynamic, etc.	64 (48)
Medication: Initiate	63 (48)
Coordinate Care/Family Communication	57 (43)
Coordinate Care/Provider Communication	54 (41)
Arrange Family Meeting	51 (39)

	N=132 No. (%) in which the code appeared at least once
Help with Decision-making	31 (23)
Consult/Referral	30 (23)
Medication Decrease	25 (19)
Cardiac Advanced Therapeutics	25 (19)
Non-cardiac Advanced Therapeutics	25 (19)
Medication Maintained	24 (18)
Spiritual Care	21 (16)
Medication Increase	13 (10
Treatment Recommendations for Symptoms	
Breathlessness	30 (23)
General Pain	24 (18)
Anxiety	18 (14)
Depression	10 (8)
Fatigue	4 (3)
Constipation	4 (3)
Sleep Problem	4 (3)
Cognitive/Mental Status	4 (3)
Anorexia	3 (2)
Dry Mouth	2 (2)
Chest Pain	1 (1)
Nausea/Vomiting	1 (1)
Diarrhea	1 (1)
Advanced Care Planning Interventions	
Discuss Hospice Referral	51 (39)
Goals of Care: Weigh & Consider	50 (38)
Discuss Prognosis	42 (32)
Discuss Illness Trajectory	40 (30)
Assist to Identify Surrogate	17 (13)