



Heart Failure Palliative Care for In-patient and Out-patient

July 18, 2018

1:00pm – 2:00pm Central



Presenter:

Lee R. Goldberg MD, MPH

Advanced Heart Failure Certification

This certification is offered by The Joint Commission in collaboration with the American Heart Association

- Assist organizations in helping patients manage chronic disease
- Reduce unwanted variations in care and improve the patient experience
- Improve efficiency and outcomes at a potential lower cost
- Position your service line to effectively face new challenges
- Unique survey approach that combines unique survey approach with what AHA has to offer
- Receive recognition of your quality program
- Promote a culture of excellence to boost retention and recruitment of talent
- As of January 1, 2019, all AHF certified organizations will be required to participate in the AHA GWTG-HF registry



**The Joint
Commission®**



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Association®**

C E R T I F I C A T I O N

Meets standards for

**Advanced Heart Failure
Certification**

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Our Presenter



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Phenotype of Heart Failure is Changing

- Improved survival
 - Medications
 - Devices
 - Primary angioplasty
- Decreased sudden death
 - ICD
 - Medications
- Appearance of low cardiac output state
- Survive to get cancer, dementia, renal failure etc.



New Devices – New Challenges

- ICD
 - PTSD/Anxiety
 - Deactivation
- VAD's
 - Poor outcome but “can’t die”
 - Deactivation



Classification of Heart Failure

Stage “Course of Disease” **Class “Symptoms at that moment”**

ACCF/AHA Stages		NYHA Functional Classification	
A	At high risk for HF but without structural heart disease or symptoms of HF	None	
B	Structural heart disease but without signs or symptoms of HF	I	No limitation of physical activity. Ordinary physical activity does not cause HF symptoms
C	Structural heart disease with prior or current symptoms of HF	I	No limitation of physical activity. Ordinary physical activity does not cause HF symptoms
		II	Slight limitation of physical activity. Comfortable at rest, but ordinary physical activity results in HF symptoms
		III	Marked limitation of physical activity. Comfortable at rest, but less than ordinary activity causes HF symptoms
		IV	Unable to carry on any physical activity without HF symptoms, or symptoms at rest
D	Refractory HF requiring specialized interventions	IV	Unable to carry on any physical activity without HF symptoms, or symptoms at rest

The minimal required therapies to prevent progression and reduce morbidity and mortality	Therapies to reduce symptoms or trigger referral to advanced therapies or hospice
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Classification of Heart Failure

Stage “Course of Disease”

Class “Symptoms at that moment”

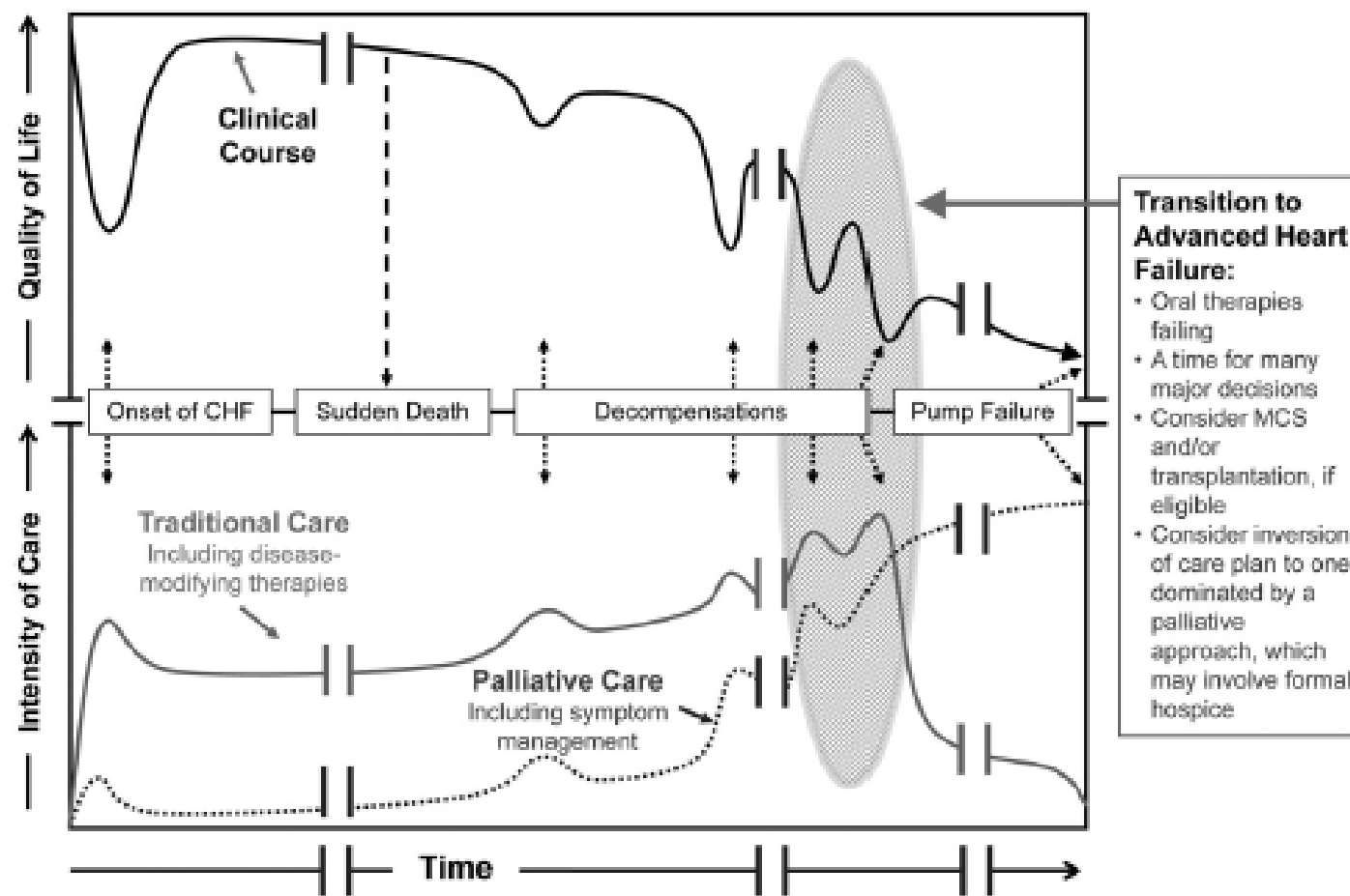
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The minimal required therapies to prevent progression and reduce morbidity and mortality

Therapies to reduce symptoms or trigger referral to advanced therapies or hospice



Trajectory of HF: Uncertain Prognosis



Allen L, et al. Circulation 125(15);2012.



Palliative Care Definition – World Health Organization

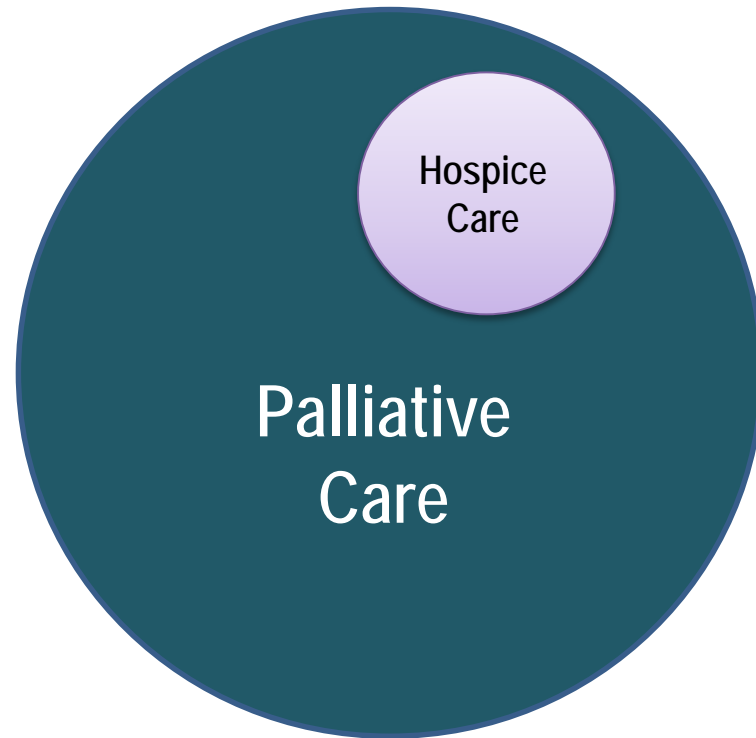
“... an approach that improves the quality of life (QOL) of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

➤ Distinct from Hospice

World Health Organization. WHO definition of palliativecare. Available at: <http://www.who.int/cancer/palliative/definition/en>. Published 2010.



Palliative Care Is Not Hospice



Khan RF et al. JAMA Intern Med. 2015 Oct;175(10):1713-5.



Palliative Care Versus Hospice

Palliative Care versus Hospice

Palliative Care	Hospice
A medical specialty	An insurance benefit
Appropriate at any time during a serious illness, independent of goals or prognosis	Appropriate when 2 or more physicians determine likely prognosis of 6 months or less
Continued curative or life-prolonging therapies available	Goal of comfort-focused care
Can monitor the patient anywhere	Provided at home, in a long-term care facility, or at an inpatient hospice

Klinedinst R, et al. (2018), <https://doi.org/10.1053/j.jvca.2018.04.047>



Models of Palliative Care

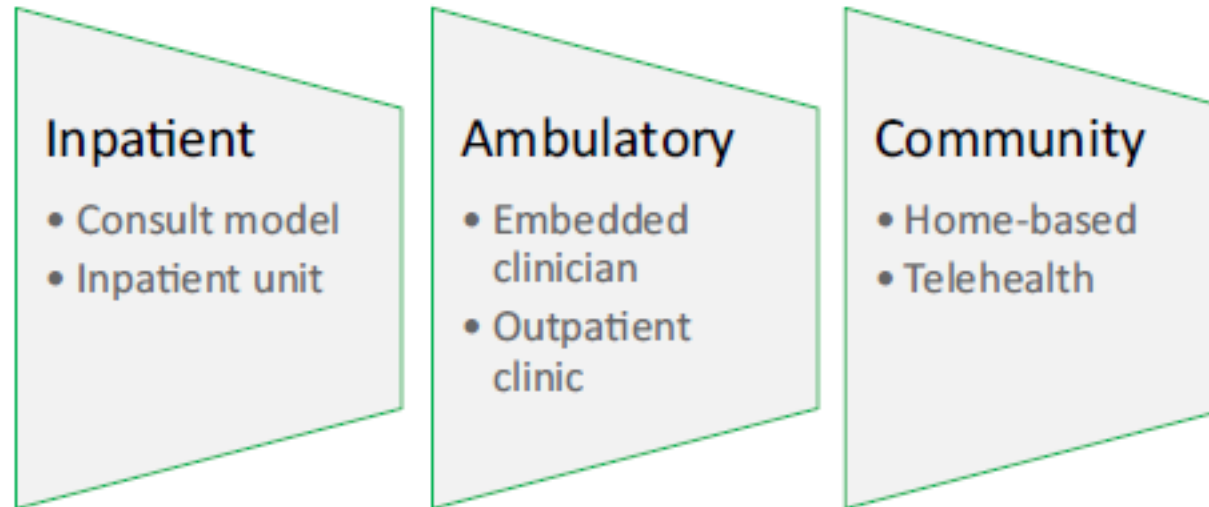


Fig 1. Models of palliative care.



Complex medical decision making

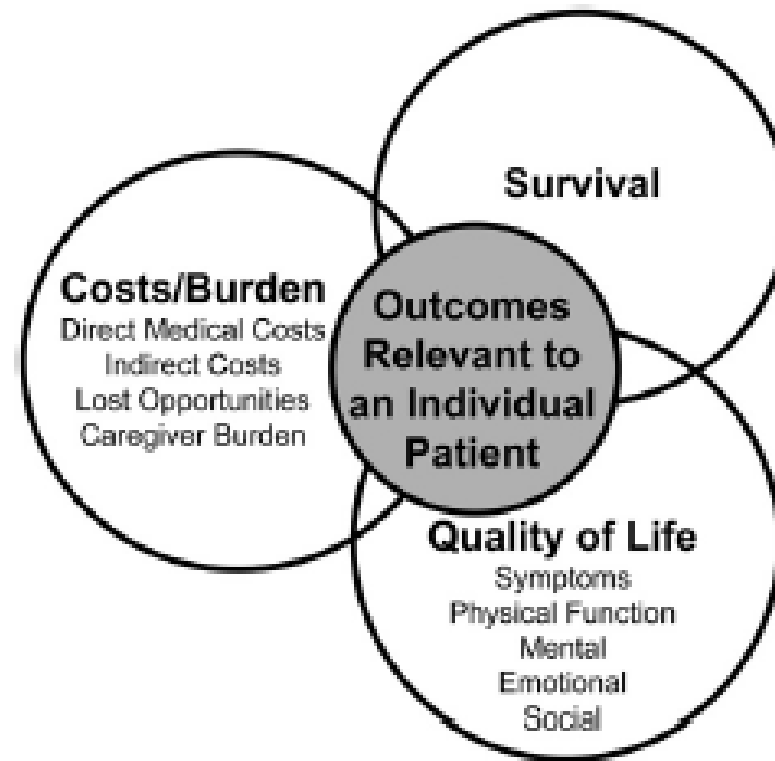


Figure 2. Prognosis is not only about expectations for survival. There are multiple domains that are of varying importance to individual patients. Adapted from Spilker.³⁸

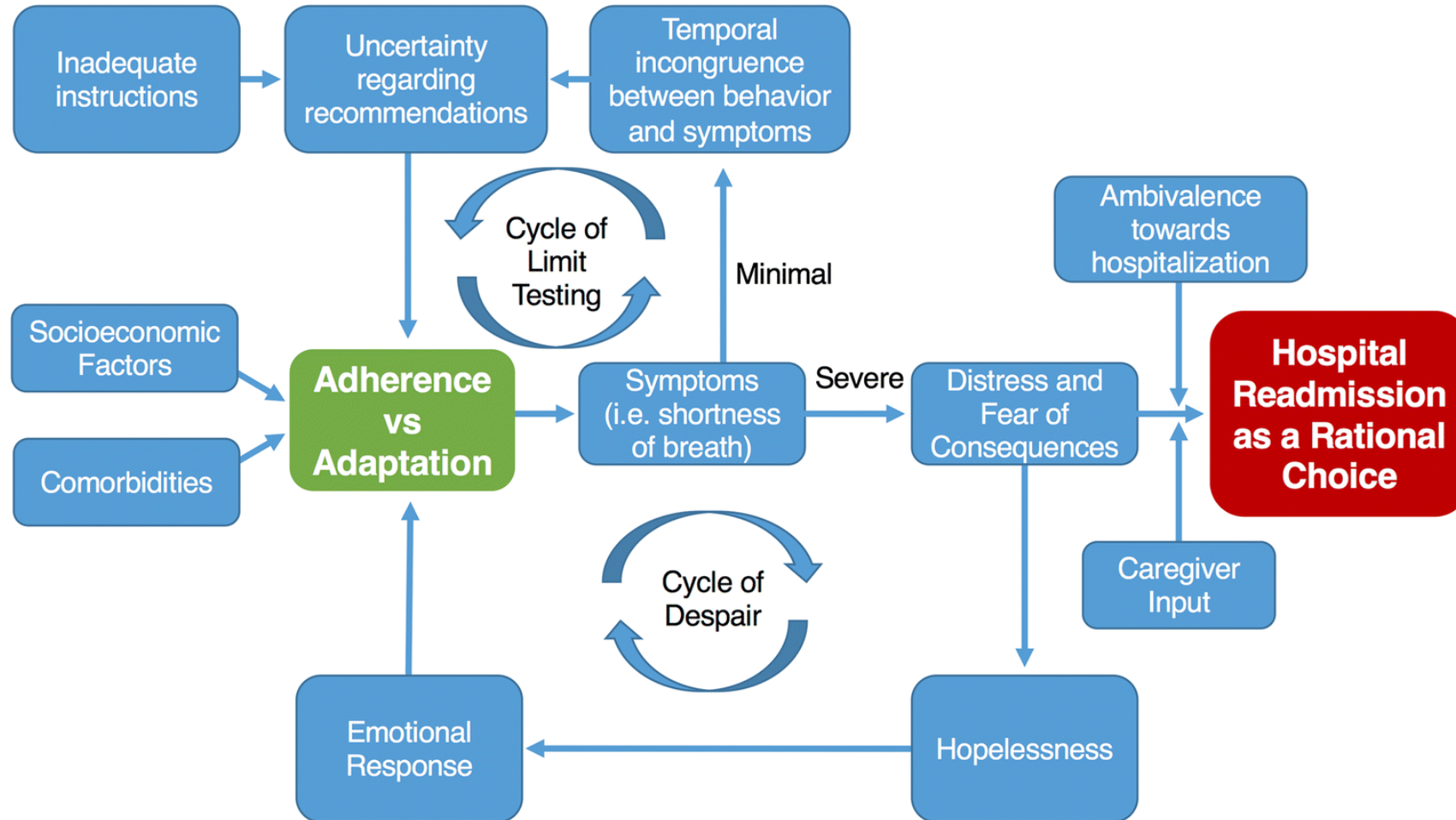
Allen L, et al. Circulation 125(15);2012.



Heart Failure Home Management Challenges and Reasons for Readmission: a Qualitative Study to Understand the Patient's Perspective

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Patient Perspectives





Benefits of early Palliative Care

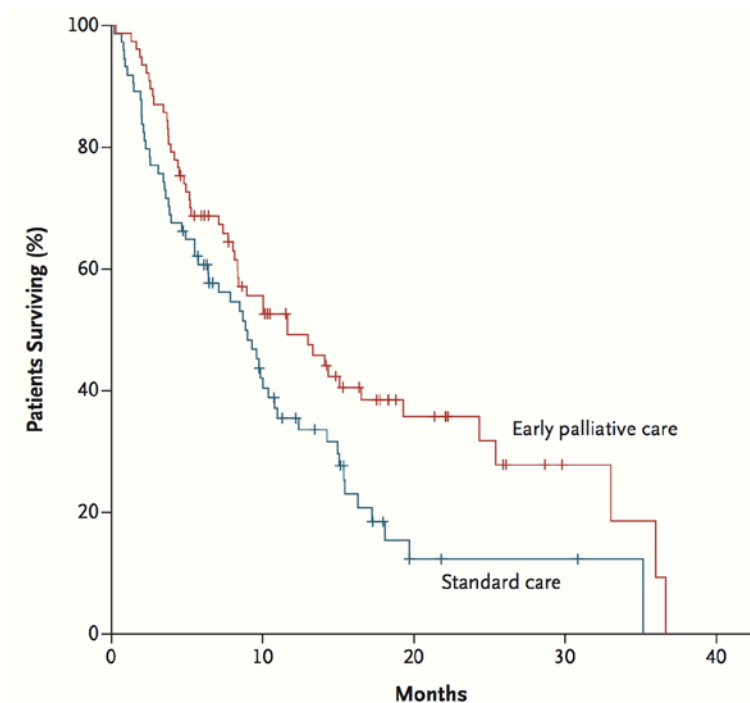
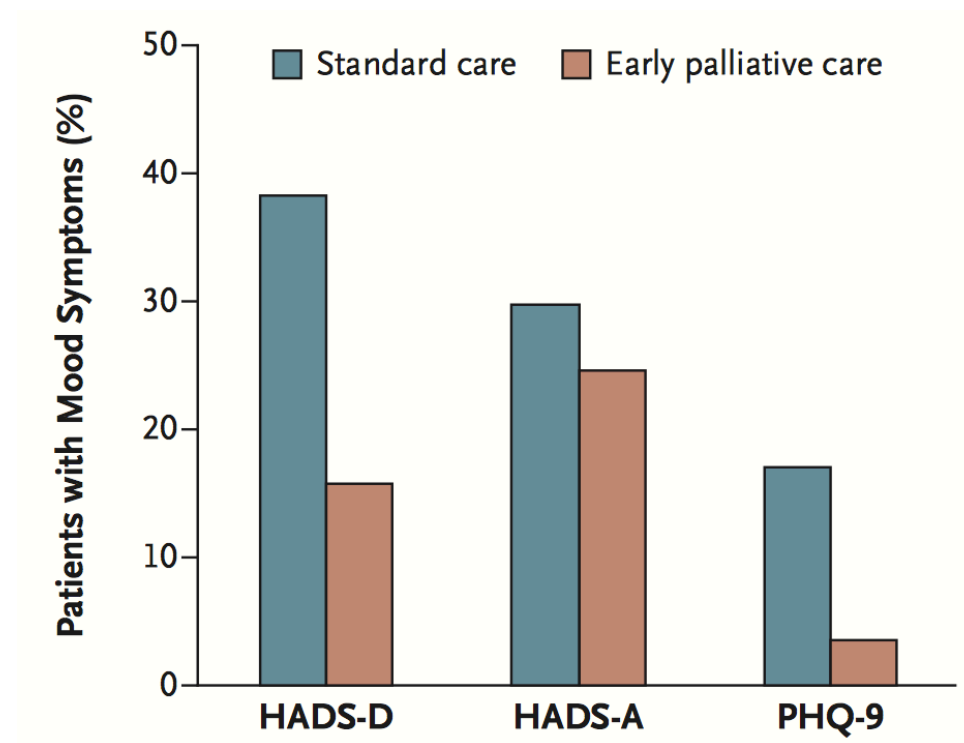
ORIGINAL ARTICLE

Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer

Jennifer S. Temel, M.D., Joseph A. Greer, Ph.D., Alona Muzikansky, M.A.,
Emily R. Gallagher, R.N., Sonal Admane, M.B., B.S., M.P.H.,
Vicki A. Jackson, M.D., M.P.H., Constance M. Dahlin, A.P.N.,
Craig D. Blinderman, M.D., Juliet Jacobsen, M.D., William F. Pirl, M.D., M.P.H.,
J. Andrew Billings, M.D., and Thomas J. Lynch, M.D.



Benefits of early Palliative Care in Lung Cancer



Improved Quality of Life and **Survival**



AHA/ASA POLICY STATEMENT

Palliative Care and Cardiovascular Disease and Stroke

**A Policy Statement From the American Heart Association/
American Stroke Association**

“Instead of serving as a reason to avoid conversation, uncertainty should be a trigger for exploration.”

Braun LT et al. Circulation. 2016 Sep 13;134(11):e198-225.



Heart Failure Patients

- Chronic life threatening condition
 - Depression
 - Psychological Pain
 - Distress
 - Symptom burden
- Very similar to patients with cancer



Palliating the Broken Heart

- Primary PC
- Specialist PC

Representative Skill Sets for Primary and Specialty Palliative Care.

Primary Palliative Care

- Basic management of pain and symptoms
- Basic management of depression and anxiety
- Basic discussions about
 - Prognosis
 - Goals of treatment
 - Suffering
 - Code status

Specialty Palliative Care

- Management of refractory pain or other symptoms
- Management of more complex depression, anxiety, grief, and existential distress
- Assistance with conflict resolution regarding goals or methods of treatment
 - Within families
 - Between staff and families
 - Among treatment teams
- Assistance in addressing cases of near futility



Heart Failure Patients are Complicated

- Many comorbidities
 - COPD
 - Gout
 - Renal failure
 - Dementia
 - Cancer
- Complexity
 - Management
 - Symptoms
 - Distress



Studies of Palliative Care in Heart Failure

Studies of Palliative Care in Heart Failure

Authors, Year Published (Ref)	Selection Criteria/ Patients Included	Study Type	Intervention	Outcome
Wiskar et al., 2017 ¹⁶	2282 patients discharged after admission for congestive HF exacerbation who received PC consult propensity matched with 2282 patients who had not	Retrospective cohort study with propensity matching	PC consult during admission	Reduced all-cause and HF-specific readmission at 9 months (p < 0.01), reduced hospital charges (p < 0.01) in intervention group
Sidebottom et al., 2015 ¹⁷	232 patients hospitalized with acute heart failure Patients in ICU, with LVADs excluded	Randomized controlled trial	PC consultation with baseline measurement of symptom burden, depression and QOL. Consults targeted spiritual well-being, symptom management, coordination of care Follow-up on as-needed basis	Improvements at 1 month in QOL (p > 0.01), symptom burden (p < 0.01), depression (p < 0.01) domains, increased advance care planning in intervention group
Rogers et al., 2017 ¹⁸	150 inpatients and outpatient at high risk of rehospitalization based on risk scores of Evaluation Study of Congestive Heart Failure and Pulmonary Artery Catheterization Effectiveness	Randomized controlled trial	PC consult with assessment of symptom control, spiritual distress, advance care planning Focus on goal-setting with patient and cardiology team	Improved symptom management on multiple scales at 6 months (p = 0.03), improved depression scores (p = 0.02), spiritual well-being (p = 0.027) in intervention group
Naylor et al., 2004 ¹⁹	239 patients ages greater than 65 years hospitalized with HF	Randomized controlled trial	Outpatient follow-up after discharge 3-month APN-directed discharge planning and home follow-up protocol	No change in rehospitalization or mortality Increased time to first readmission or death (p = 0.26), reduced readmission rates (p = 0.047), lower total mean costs (p < 0.05) in intervention group
Wong et al., 2016 ²⁰ ; Ng and Wong, 2018 ²¹	84 patients admitted to hospital meeting 2 or more indicators of end stage HF	Randomized controlled trial	Predischarge meeting and 4-week post-discharge telephone and in-person follow-up with ongoing discussion of disease management and treatment preferences	Reduced readmissions at 12 weeks in intervention group (p = 0.0009), significant improvements in depression, dyspnea, and overall symptom and QOL scores
Branstrom et al., 2014 ²²	72 outpatients with NYHA stage III or IV heart failure with at least 1 hospitalization in the past 6 months or documentation of increased support needs	Randomized controlled trial	Intensive identification and management of medical, psychosocial, and spiritual needs by physician; subsequent nurse-led palliative care	Improvement in quality of life, symptom burden, self-efficacy, and NYHA class in intervention group vs. control, reduced rehospitalizations in intervention group

APN, advanced practice nurse; HF, heart failure; ICU, intensive care unit; LVAD, left ventricular assist device; NYHA, New York Heart Association; PC, palliative care; QOL, quality of life.

Klinedinst R, et al. (2018), <https://doi.org/10.1053/j.jvca.2018.04.047>



Palliative Care and Readmission

Table 1 *Baseline demographic and patient characteristics for patients referred to palliative care and those that did not get referred. Only patients who survived to hospital discharge for their index admission were included in the analysis*

	Overall cohort			Propensity-matched cohort		
	Palliative care consult (n = 2287)	No palliative care consult (n = 100 459)	P	Palliative care consult (n = 2282)	No palliative care consult (n = 2282)	P
Age in years, mean (SD)	80.9 (11.1)	72.7 (14.1)	<0.01	80.9 (11.1)	81.7 (10.3)	0.06
Any 9-month readmission, n (%)	526 (21.8)	60 170 (59.8)	<0.01	525 (29.0)	1757 (63.2)	<0.01
9 month CHF readmission, n (%)	226 (9.3)	28 197 (28.0)	<0.01	226 (9.3)	514 (22.4)	<0.01
Length of stay in days, median (IQR)	5.1 (2.9–8.7)	3.5 (2.0–5.9)	<0.01	5.1 (2.8–8.8)	4.1 (2.3–6.7)	<0.01
Female sex, n (%)	1224 (54.0)	48 483 (48.6)	<0.01	1223 (54.0)	1261 (55.0)	0.54
Insurance coverage, n (%)	2158 (94.7)	94 901 (94.7)	0.98	2158 (94.9)	2183 (96.0)	0.11
Discharge location, n (%)						
Home	289 (10.7)	53 514 (52.7)		289 (10.8)	783 (34.2)	
Skilled nursing facility	982 (44.5)	19 000 (19.5)		978 (44.4)	804 (36.1)	
Hospice / Home care	934 (41.4)	25 622 (25.4)		933 (41.5)	657 (28.2)	
Other	82 (3.3)	2323 (2.3)	<0.01	82 (3.3)	38 (1.5)	<0.01
Teaching hospital, n (%)	1080 (47.8)	43 771 (44.6)	0.11	1078 (47.8)	1052 (47.0)	0.71
Do not resuscitate status, n (%)	1259 (52.4)	7906 (7.9)	<0.01	1254 (52.4)	1242 (54.0)	0.37
Non metastatic cancer, n (%)	74 (3.0)	1638 (1.7)	<0.01	73 (3.1)	72 (3.0)	0.94
Metastatic cancer, n (%)	68 (2.7)	895 (0.9)	<0.01	68 (2.8)	69 (2.9)	0.87

SD, standard deviation; IQR, interquartile range. Propensity-matched analysis is displayed on the right hand side of the table, patients were matched 1 : 1 on the propensity to receive a palliative care referral during the index hospitalization



Inpatient Palliative Care Consults

TABLE 2. COMPARISON OF CHANGE FROM BASELINE TO 1 AND 3 MONTHS, ADJUSTED FOR AGE, GENDER, AND MARITAL STATUS

	Change at 1 month from baseline				Change at 3 months from baseline			
	Intervention (n = 86) Mean change	Control (n = 89) Mean change	Mean difference between groups (CI)	p-value	Intervention (n = 79) Mean change	Control (n = 88) Mean change	Mean difference between groups (CI)	P value
<i>Edmonton Symptom Assessment Scale</i>								
Pain	0.63	0.87	−0.24 (−0.54, 0.05)	0.109	0.93	0.49	0.44 (0.13, 0.75)	0.005
Tiredness	1.78	0.50	1.28 (0.97, 1.58)	0.000	2.06	1.20	0.86 (0.55, 1.17)	0.000
Nausea	0.08	0.29	−0.20 (−0.50, 0.09)	0.179	0.20	0.38	−0.18 (−0.49, 0.13)	0.260
Depression	0.77	0.05	0.72 (0.42, 1.03)	0.000	0.92	−0.10	1.01 (0.70, 1.32)	0.000
Anxiety	1.06	0.65	0.42 (0.12, 0.72)	0.007	1.27	0.89	0.38 (0.07, 0.69)	0.017
Drowsiness	1.32	1.06	0.27 (−0.03, 0.56)	0.083	1.63	1.51	0.12 (−0.19, 0.43)	0.442
Appetite	−0.19	−0.41	0.22 (−0.08, 0.52)	0.152	0.38	−0.05	0.44 (0.13, 0.75)	0.005
Well-being	0.37	0.24	0.13 (−0.17, 0.43)	0.393	0.79	0.64	0.15 (−0.15, 0.46)	0.333
Short of breath	2.55	1.45	1.10 (0.80, 1.40)	0.000	2.82	1.74	1.08 (0.77, 1.39)	0.000
Total (range 0–90)	8.39	4.70	3.69 (3.39, 3.99)	0.000	11.00	6.70	4.31 (4.00, 4.62)	0.000
<i>PHQ-9</i>								
Little interest or pleasure in doing things	0.52	0.41	0.10 (−0.20, 0.41)	0.504	0.43	0.42	0.01 (−0.30, 0.32)	0.953
Feeling down, depressed, or hopeless	0.35	0.17	0.18 (−0.12, 0.49)	0.232	0.30	0.34	−0.04 (−0.36, 0.27)	0.781
Trouble falling asleep or staying asleep, or sleeping too much	0.43	0.30	0.13 (−0.17, 0.43)	0.407	0.35	0.43	−0.08 (−0.39, 0.23)	0.608
Feeling tired or having little energy	0.61	0.48	0.14 (−0.17, 0.44)	0.374	0.77	0.64	0.13 (−0.18, 0.44)	0.422
Poor appetite or overeating	0.20	0.02	0.18 (−0.13, 0.49)	0.253	0.37	−0.09	0.46 (0.15, 0.77)	0.004
Feeling bad about yourself	0.29	−0.04	0.33 (0.03, 0.63)	0.033	0.27	0.04	0.23 (−0.08, 0.55)	0.140
Trouble concentrating	0.15	0.11	0.04 (−0.26, 0.34)	0.789	0.08	0.25	−0.17 (−0.48, 0.14)	0.286
Motor retardation or agitation	0.27	0.04	0.23 (−0.07, 0.53)	0.135	0.27	0.10	0.17 (−0.14, 0.48)	0.277
Thoughts that you would be better off dead, or of hurting yourself	0.13	0.05	0.07 (−0.23, 0.38)	0.637	0.06	0.08	−0.02 (−0.33, 0.29)	0.888
Total (range 0–27)	2.99	1.56	1.42 (1.12, 1.73)	0.000	2.90	2.18	0.72 (0.41, 1.03)	0.000
<i>Minnesota Living with Heart Failure Questionnaire</i>								
Physical subscale	8.27	4.75	3.51 (3.21, 3.82)	0.000	8.01	6.76	1.25 (0.94, 1.57)	0.000
Emotional subscale	2.19	1.23	0.96 (0.65, 1.27)	0.000	3.65	1.92	1.72 (1.41, 2.04)	0.000
Total (range 0–105)	12.92	8.00	4.92 (4.61, 5.23)	0.000	14.86	11.80	3.06 (2.75, 3.37)	0.000

Calculated as baseline minus 1 month or 3 month scores. Positive number indicates improvement since baseline and negative indicates worse condition than baseline.
CI, confidence interval; PHQ-9, Patient Health Questionnaire-9.



Inpatient Palliative Care Consults

- Improved at 3 months
 - Quality of life
 - Symptom burden
 - Depressive symptoms
- More likely to have an advanced care plan



Benefits of Palliative Care in Heart Failure Patients

Palliative Care in Heart Failure

The PAL-HF Randomized, Controlled Clinical Trial

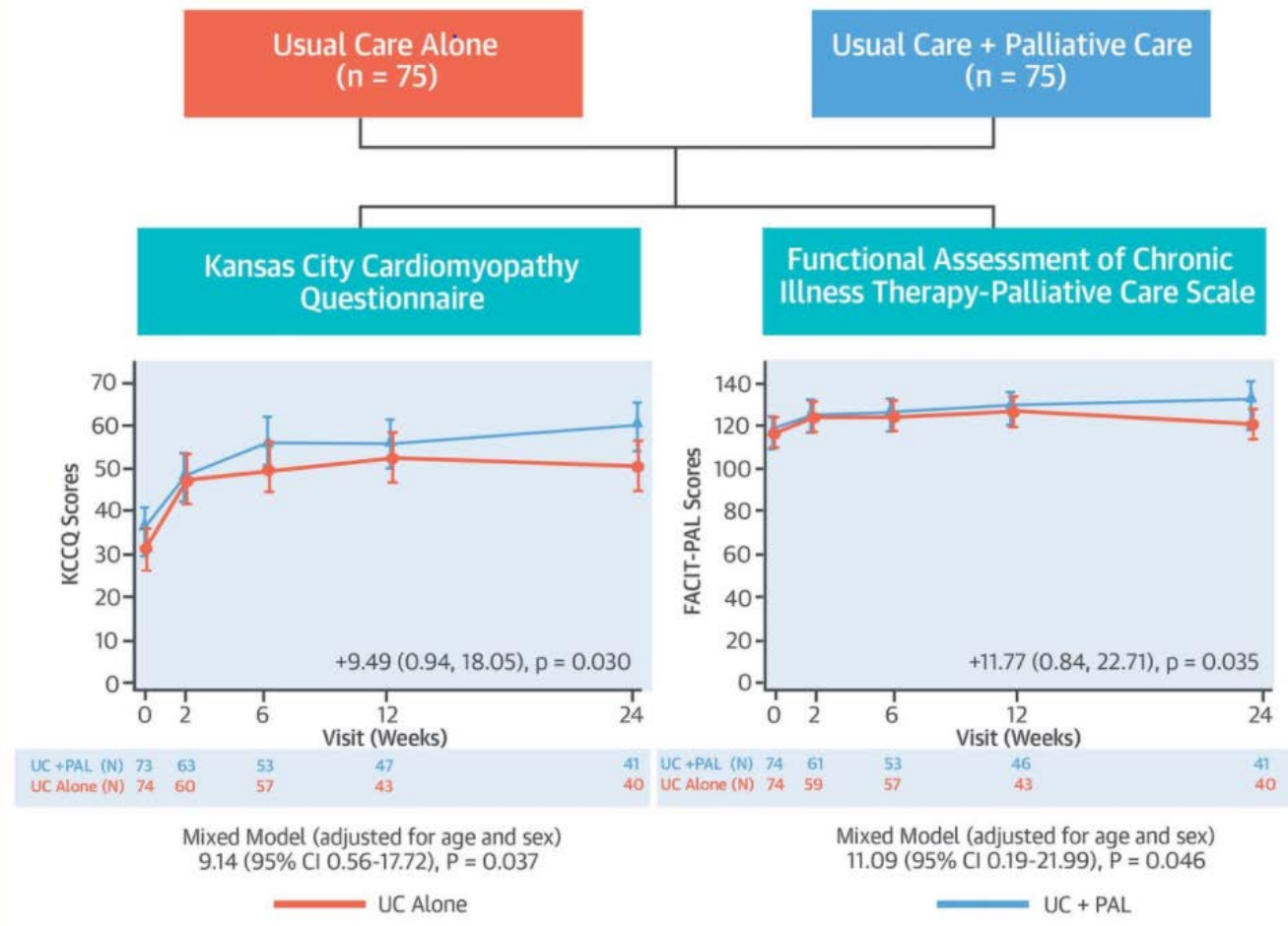


Joseph G. Rogers, MD,^{a,b} Chetan B. Patel, MD,^{a,b} Robert J. Mentz, MD,^{a,b} Bradi B. Granger, PhD, MSN, RN,^c Karen E. Steinhauser, PhD,^{a,d} Mona Fiuzat, PHARM D,^a Patricia A. Adams, BSN, CCRC,^a Adam Speck, BS,^a Kimberly S. Johnson, MD,^{a,b} Arun Krishnamoorthy, MD,^e Hongqiu Yang, PhD,^b Kevin J. Anstrom, PhD,^{b,f} Gwen C. Dodson, MSN,^a Donald H. Taylor, Jr, PhD, MPA,^{a,g,h} Jerry L. Kirchner, BS, CCRP,^b Daniel B. Mark, MD,^{a,b} Christopher M. O'Connor, MD,^{a,i} James A. Tulsky, MD,^{j,k}



Benefits of Palliative Care

CENTRAL ILLUSTRATION: The PAL-HF Study Randomized 150 Patients With Advanced Heart Failure to Usual Care or Usual Care + a Multidimensional Palliative Care Intervention





Randomized Trial

ORIGINAL ARTICLE

Effects of a transitional palliative care model on patients with end-stage heart failure: a randomised controlled trial

Frances Kam Yuet Wong,¹ Alina Yee Man Ng,¹ Paul Hong Lee,¹ Po-tin Lam,² Jeffrey Sheung Ching Ng,³ Nancy Hiu Yim Ng,² Michael Mau Kwong Sham⁴

- Randomized control trial of transitional palliative care
 - Weekly visits at home for 4 weeks
 - Monthly visits to 1 year

Wong FKY, et al. *Heart* 2016;**102**:1100–1108.



Results

Table 2 Readmission at 4 and 12 weeks

	Control (n=41)	Intervention (n=43)	p Value
Number of readmissions at 4 weeks (mean, SE)	0.41 (0.10)	0.21 (0.07)	0.10
Number of readmissions at 12 weeks (mean, SE)**	1.10 (0.16)	0.42 (0.10)	0.001
Readmissions within 28 days (n, %)			
No	29 (70.7%)	34 (79.1%)	0.38
Yes	12 (29.3%)	9 (20.9%)	
Readmissions within 84 days (n, %)*			
No	16 (39.0%)	29 (67.4%)	0.009
Yes	25 (61.0%)	14 (33.6%)	

Tested using Poisson regression and χ^2 test. *p<0.05; **p<0.01.

Table 3 Change in ESAS at O2 (n=68)

	Deterioration	Control (n=31)		Deterioration	Intervention (n=37)	
		No change	Improvement		No change	Improvement
Frequency (%)						
Pain	10 (32.3%)	11 (35.5%)	10 (32.3%)	8 (21.6%)	15 (40.5%)	14 (37.8%)
Tiredness	11 (35.5%)	10 (32.3%)	10 (32.3%)	7 (18.9%)	13 (35.1%)	17 (45.9%)
Nausea	1 (3.2%)	30 (96.8%)	0 (0.0%)	1 (2.7%)	34 (91.9%)	2 (5.4%)
Depression*	11 (35.5%)	15 (48.4%)	5 (16.1%)	7 (18.9%)	13 (35.1%)	17 (45.9%)
Anxiety	8 (25.8%)	16 (51.6%)	7 (22.6%)	8 (21.6%)	13 (35.1%)	16 (43.2%)
Drowsiness	3 (9.7%)	25 (80.6%)	3 (9.7%)	1 (2.7%)	31 (83.8%)	5 (13.5%)
Loss of appetite	10 (32.3%)	9 (29.0%)	12 (38.7%)	7 (18.9%)	16 (43.2%)	14 (37.8%)
Sense of well-being	14 (45.2%)	10 (32.3%)	7 (22.6%)	14 (37.8%)	9 (24.3%)	14 (37.8%)
Dyspnoea*	10 (32.3%)	12 (38.7%)	9 (29.0%)	7 (18.9%)	7 (18.9%)	23 (62.2%)
Total*	12 (41.4%)	5 (17.2%)	12 (41.4%)	7 (18.9%)	3 (8.1%)	27 (73.0%)

Tests using χ^2 ; *p<0.05.

Note: the MCID cut-offs for improvement/deterioration of each symptom²⁷ and total²⁸ were: pain 1.4/−1, tiredness 1.5/−1.5, nausea 1.6/−2.3, depression 1/−1.8, anxiety 1.7/−1.4, drowsiness 0.8/−2, loss of appetite 1.2/−2.1, sense of well-being 1.2/−0.8, dyspnoea 1.2/−1.3 and total 5.7/−2.9.

ESAS, Edmonton Symptom Assessment Scale; MCID, minimal clinically important difference.



High symptom burden

Hospitalized patients with HF

Table. Symptom Severity and Lack of Improvement

Symptom	ESAS Score, Mean (SD)		P Value ^a	Patients Who Reported No Improvement in Symptom Severity, No. (%)
	Baseline Interview	Follow-up Interview		
Pain	3.4 (3.3)	3.0 (3.3)	.21	35 (41)
Shortness of breath	4.1 (3.4)	3.0 (3.1)	.001	35 (41)
Depression	3.4 (3.3)	3.0 (3.1)	.26	35 (41)
Loss of interest	3.4 (3.3)	3.0 (3.1)	.26	35 (41)
Exhaustion	3.4 (3.3)	3.0 (3.1)	.26	35 (41)
Weakness	3.4 (3.3)	3.0 (3.1)	.26	35 (41)
Loss of appetite	3.4 (3.3)	3.0 (3.1)	.26	35 (41)
Weight loss	3.4 (3.3)	3.0 (3.1)	.26	35 (41)
Swelling	3.4 (3.3)	3.0 (3.1)	.26	35 (41)
Anxiety	3.4 (3.3)	3.0 (3.1)	.26	35 (41)
Decreased well-being	5.2 (2.4)	4.5 (1.9)	.02	45 (52)
Edema	4.1 (3.4)	2.2 (2.5)	<.001	18 (21)

No improvement in symptoms after hospitalizations
68% HF pts interested in receiving PC



Indications for Referral

Indications for Palliative Care Referral in Patients with Heart Failure (HF)

Symptom Needs	Psychosocial Needs	Transitions in Management
New York Heart Association Class III/IV symptoms	Caregiver support	Left ventricular assist device evaluation
Frequent readmissions for HF	Goals of care	Transplant evaluation
Recurrent implantable cardioverter-defibrillator shocks	Supportive counseling	Transcatheter aortic valve replacement evaluation
Refractory angina	Advance care planning	Initiation of home inotropic therapy
Anxiety or depression impacting quality of life and disease management		Hospice referral/ discussion
		Withdrawal of life-prolonging interventions

Klinedinst R, et al. (2018), <https://doi.org/10.1053/j.jvca.2018.04.047>



Heart Failure Advanced Care Planning

- Define goals
 - Intubation
 - Dialysis
 - Re-hospitalization
- Deactivate ICD
 - Maintain BiV pacing functions



Timeline for Palliative Care in Heart Failure

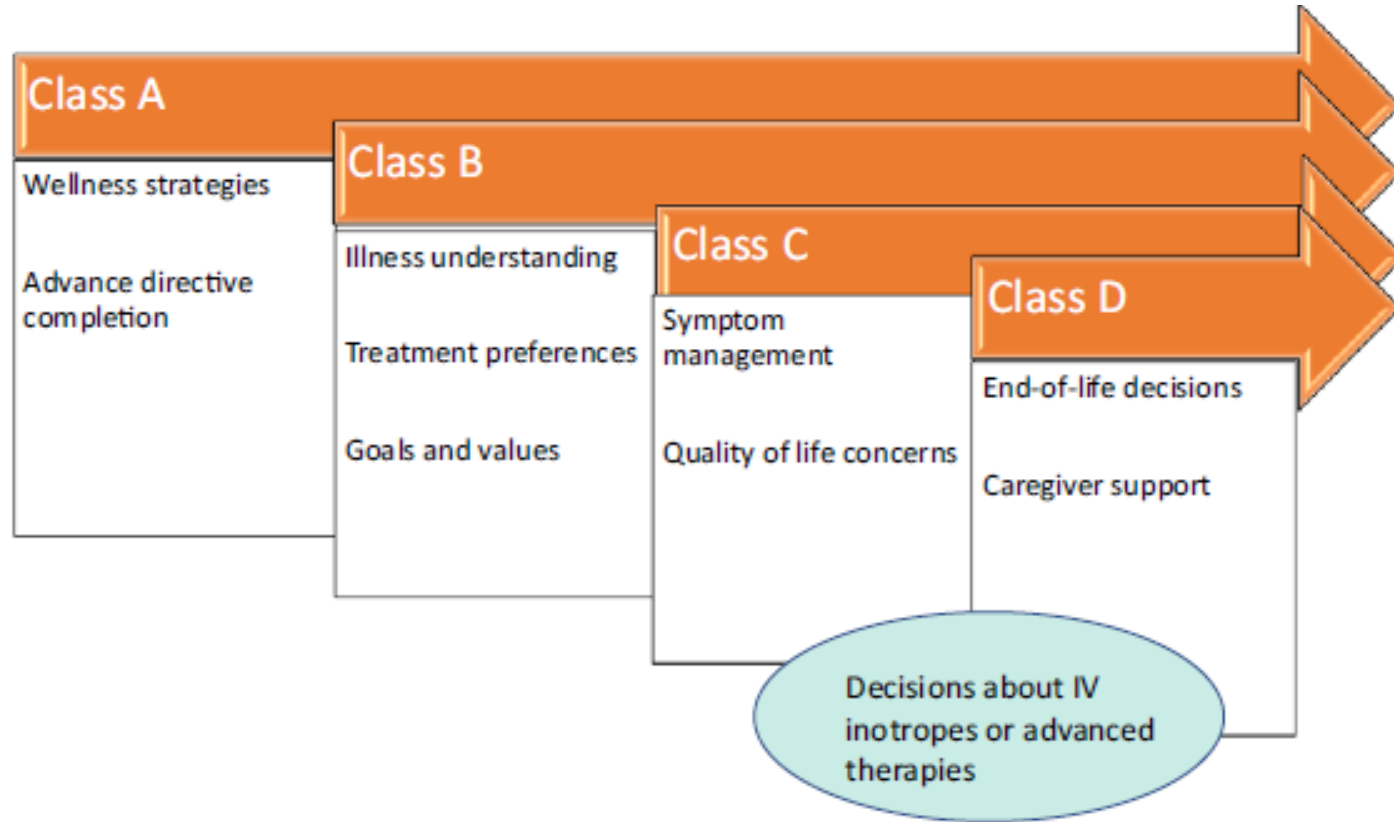


Fig 2. Timeline for palliative care in heart failure.



Inotropes – ACC/AHA Guidelines

Indications for intravenous inotropic support	Class	LOE
Cardiogenic shock pending definite therapy or resolution	I	C
Bridge to transplant or mechanical circulatory support in stage D heart failure refractory to guideline-directed medical therapy	IIa	B
Short-term support for threatened end-organ dysfunction in hospitalized patients with stage D and severe HFrEF	IIb	B
Long-term support with continuous infusion palliative therapy in selected stage D heart failure	IIb	B
Routine intravenous use, either continuous or intermittent, is potentially harmful in stage D heart failure	III	B
Short-term intravenous use in hospitalized patients without evidence of shock or threatened end-organ performance is potentially harmful	III	B

Class class of recommendation: *I* is indicated, *IIa* should be considered, *IIb* may be considered, *III* is not recommended, *LOE* level of evidence: *B* limited populations evaluated (data from either one single randomized trial or nonrandomized studies), *C* expert consensus, *HFrEF* heart failure with reduced ejection fraction



Palliative Milrinone

- Can prevent hospitalizations and transiently improve quality of life
- 50% mortality at 6 months
- 90% mortality at 1 year
- Requires IV access – often PICC line
- By definition need palliative care consult
 - Improved symptoms may delay palliative care
 - Initiation of inotropes is a “sentinel” event
- If consideration of MCD or Transplant need expedited work-up

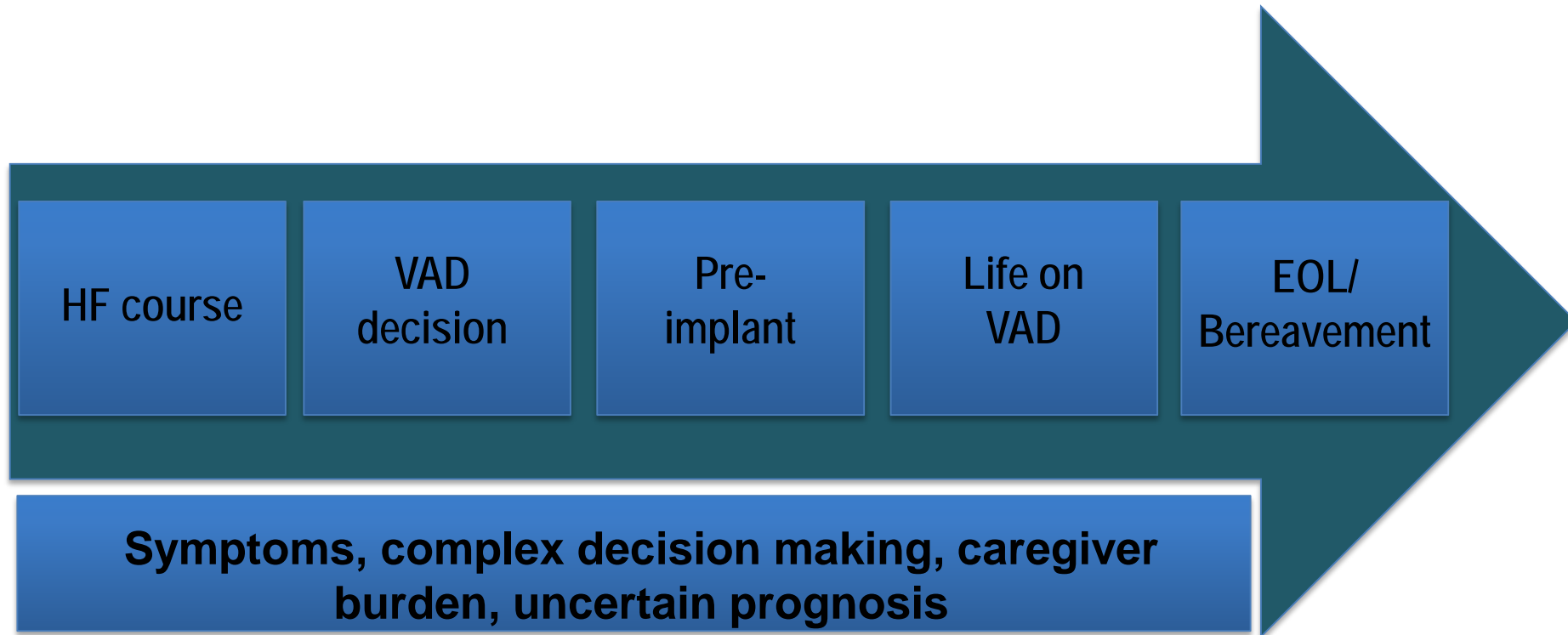


Mechanical Circulatory Support

- Destination therapy
 - Not candidate for transplant
 - More comorbidities
 - More psychosocial challenges



The MCS Journey



Adapted from JN Kirkpatrick



Complex Decision Making



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



High caregiver burden

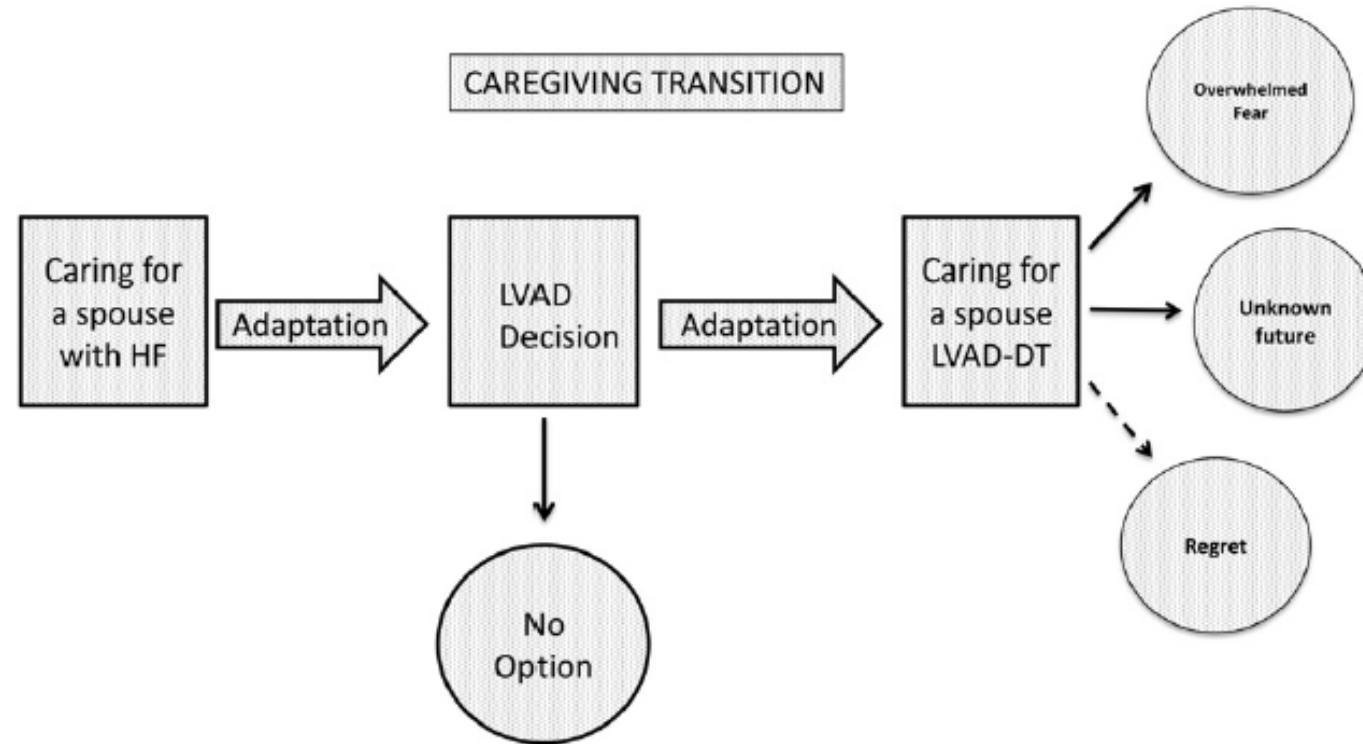
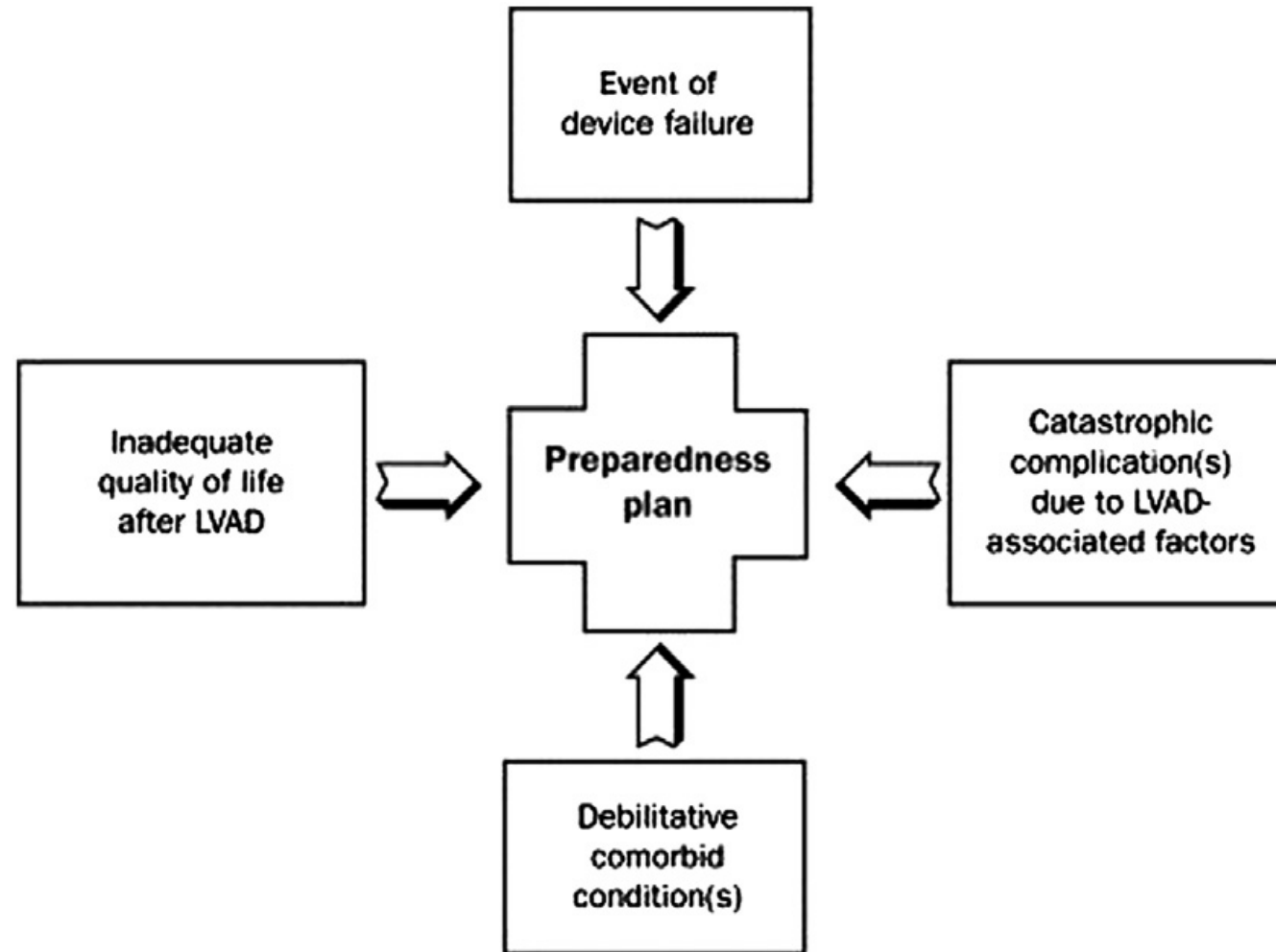


Fig. 1. Caregiving transition.



Pre-implant: Preparedness Planning





Post-implant

Intermedics Continuous Flow LVAD/BiVAD Implants: 2008 – 2014, n=12030

Instantaneous Death Rate (Hazard) for selected causes

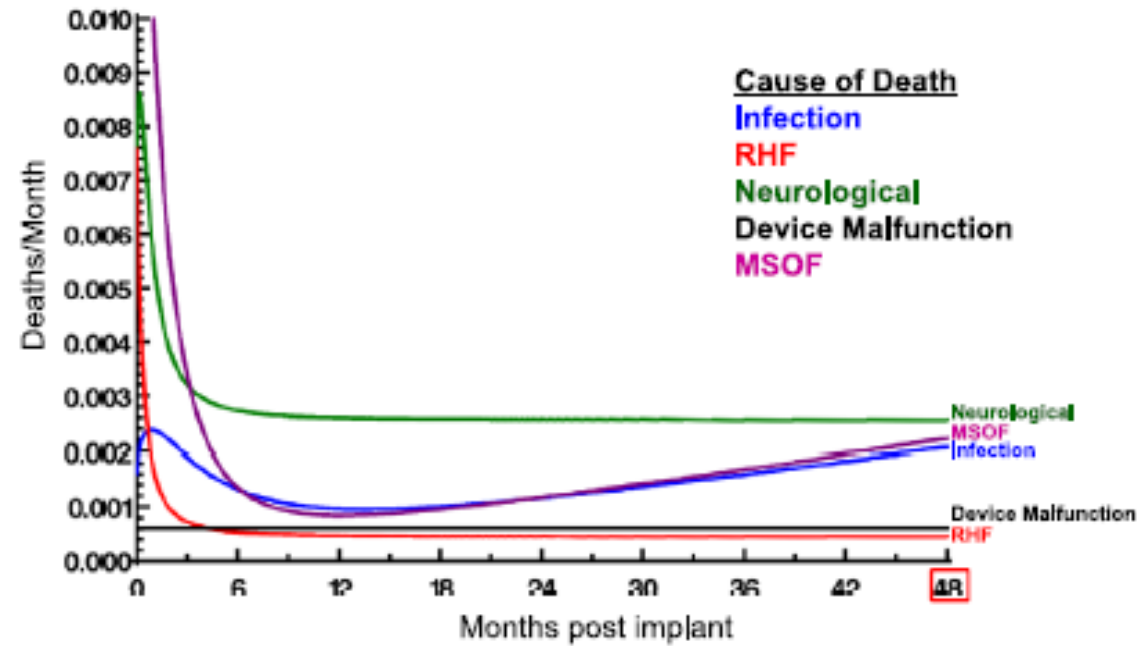


Figure 10 Hazard function curves indicating the instantaneous risk of death over time for the major causes/modes of death. RHF, right heart failure; MSOF, multisystem organ failure.

Kirklin JK, et al. J Heart Lung Transplant. 2015 Dec;34(12):1495-504.



Studies of Palliative Care in LVAD

Studies of the Role of Palliative Care in Patients with Left Ventricular Assist Devices (LVADs)

Authors, Year Published (Ref)	Selection Criteria	Study Type	Intervention	Outcome
Sinha et al., 2017 ³⁷	122 patients undergoing LVAD implantation, both destination (DT) and bridge to transplantation therapy (BTT) at a single institution	Retrospective chart review	Automated trigger of interdisciplinary palliative care (PC) consult for all patients undergoing LVAD evaluation, compared to pre-intervention control group.	Percentage of total PC consults placed before LVAD implantation increased from 17.2% (11) before protocol to 96.6% (56) after protocol ($p < 0.0001$) Documented surrogate decision maker increased from 40.6% (26) before protocol to 98.3% (57) after protocol ($p < 0.0001$).
Salomon et al., 2018 ³⁸	51 patients receiving LVADs at a single urban academic medical left	Retrospective chart review	Use of an electronic order by cardiothoracic surgery team to initiate PC consult (9 months intervention) compared with use of PC physician participating in interdisciplinary LVAD rounds (3 months intervention).	During electronic order intervention, 35% of patients received a PC consult compared with 71% of patients during PC physician rounding intervention Symptom assessment, psychosocial assessment, and advance care planning were performed in 100% of consults
Nakagawa et al., 2017 ³⁹	112 patients undergoing evaluation for DT (75) or BTT (37) LVAD at a single centre	Prospective single arm study	Mandatory PC consult during pre-LVAD evaluation, using a semi-structured interview script based on the PC communication literature	All patients could express what makes their life meaningful, and 101 (92%) could discuss possible complications. 79 patients (70.5%) could describe their unacceptable health state There was no difference between DT and BTT groups Family awareness increased significantly from 33% to 58% after intervention ($p < 0.01$).
Swetz et al., 2011 ⁴⁰	19 patients with DT LVAD at single tertiary care centre	Retrospective chart review	Interdisciplinary PC consult at time of evaluation for destination LVAD Focus on preparedness planning: care preferences in the case of poor quality of life, acute device failure, catastrophic complication, or progressive comorbid condition	13 patients received a PC consult; 6 did not 11 patients (85%) in the intervention group had documented advance directives compared with 3 patients (50%) in the group that did not undergo a PC consultation ($P = .26$) Considering the small sample size, the significance of this is unknown
Allen et al., 2018 ⁴²	248 adult patients being evaluated for LVAD as a DT at 6 LVAD implanting centres in the United States	Randomized controlled trial	Delivery of a 2.5-hour clinician-directed decision support training and use of a 26-minute video and 8-page pamphlet decision aid Intervention was compared with existing evaluation process at each site, using institution-specific materials	The intervention improved patient decision quality, measured by patient knowledge and concordance between stated values, and patient-reported treatment choice It did not improve concordance between stated values and actual treatment received The LVAD implantation rate was substantially lower in the intervention compared with the control group



LVAD Deactivation

- Complicated volitional process
 - On part of patients, caregivers, providers
- High stress on caregivers as surrogate decision makers

Vinay Kini, James N. Kirkpatrick. J Cardiothorac Vasc Anesth.
2013 Oct;27(5):1051-2.



LVAD Deactivation Logisitics

TABLE 1. BASIC DEACTIVATION SEQUENCE CHECKLIST FOR HEARTMATE II LVAD

-
- a. Unscrew small black nickel-sized battery in “System Driver” (also called controller) to disable back-up alarms.
 - b. Press alarm silence button on controller.
 - c. Remove power from controller by removing the patient cable (also referred to as the Y-cable) coming from the main power base unit (simultaneous removal of both cables will limit alarms).
 - d. Detach controller from patient (cord going from LVAD driveline exiting patient to the controller).

If deactivation occurs sequentially and not simultaneously, there is the risk of the device alarming due to low power or low flow, which can be distressing to families.

Gafford EF, et al. J Palliat Med 2013;16:980e982.



Specialist PC for MCS patients

Regulatory Requirement

- Impartial voice in decision making
- Facilitator of advanced care planning
- Contributor to improved patient and family experience
- Support for MCS team members
- Support for transition to hospice and MCS deactivation



End of Life Scenarios

End-stage Heart Failure

- Poor QOL despite medical/device therapies
- Progression of comorbid conditions
 - ESRD
 - Cancer
 - Dementia
- Incompatibility with goals of care



Challenges

- Most providers do not receive palliative care training
- Discussing death is challenging
- Perception of “failure” or “letting down” patient and their family
- Better to have act of “commission” versus “omission”
- Misunderstanding of the power of palliative care – improved QOL, improved survival



Benefits

- Empower patients and families
 - Restore their “voice”
 - Avoid conflicts
- Respect preferences and goals
- Reduce suffering
- Extend survival



Conversations

- Define limits of current therapies
- Provide options
 - Advanced therapies or why not
 - Palliative inotropes
 - Deactivate ICD
 - Re-hospitalization, intubation, dialysis, etc.
- Define role of the “proxy”
- Encourage communication
 - Gift of defining wishes to avoid conflict
- Introduce palliative care



Systems to Provide Earlier Referral

- Mortality score calculated for each patient
- Provided to staff caring for patient
- Set threshold for referral to “pre-hospice” homecare
- Set threshold for referral for inpatient palliative care consult
- Access to outpatient palliative care consults



Ominous prognostic factors

Intolerance of beta-blockers

Intolerance of ACEi/ARBs

Recurrent hospitalizations

Need for inotropes

Hyponatremia

Progressive renal insufficiency



No one factor is “predictive” enough – combine and weight several into a predictive “model”



Referral to Advanced Therapy

Remember acronym to assist in decision making for referral to advanced heart failure specialist:

I-NEED-HELP (also see *Table 6*)

I: IV inotropes

N: NYHA IIIB/IV or persistently elevated natriuretic peptides

E: End-organ dysfunction

E: Ejection fraction $\leq 35\%$

D: Defibrillator shocks

H: Hospitalizations >1

E: Edema despite escalating diuretics

L: Low blood pressure, high heart rate

P: Prognostic medication – progressive intolerance or down-titration of GDMT



Penn “Wired-Way”

- Using 6 month mortality predictive model
- Refer patients to home care with a palliative care component
 - Provide additional services
 - IV diuretic escalation
 - Discussion around goals of care and wishes



Benefits of Prognostic Models



TABLE 1. Potential Benefits of Using Prognostic Models for Heart Failure

Allows patients and families to have a realistic expectation of the prognosis

Allows appropriate allocation of resources, including transplantation, mechanical circulatory assist devices, and implantable defibrillators

Allows selection of therapies most likely to positively affect the quality and quantity of life

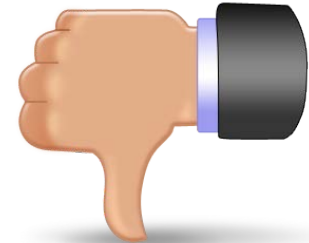
Promotes open, honest communication between clinicians, patients, and their families to define the goals of therapy

Goldberg, Jessup [Circulation](#) 2007; 116:360



Hazards of Prognostic Models

TABLE 2. Hazards of Using Prognostic Models for Heart Failure



The model was derived from a different population of patients
Patient compliance, preferences, or attitudes are not incorporated
New therapies become available, making the models obsolete
The patient is not compensated or on evidence-based therapies
Scores from the models will replace informed, compassionate,
clinician–patient conversations

Goldberg, Jessup *Circulation* 2007; 116:360



Conclusions

- Palliative care provides improved quality of life and survival in heart failure patients
- Palliative care reduces readmissions and assists patients and families define advanced care plans
- Many patients are referred to late due to lack of comfort of providers and patients – use models to help
- All team members should assess for the need for palliative care

Contact Us to Learn More

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Thank you for your active participation and
contributions to GWTG-Heart Failure!