

Nursing concerns with palliative care and at the end-of-life in patients with heart failure

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Abstract: Patients with chronic heart failure (HF) suffer from numerous symptoms and quality-of-life (QOL) concerns, and thus, palliative care, a multidisciplinary approach that includes the family and focuses on the improvement of patients' and their families' QOL through the relief of physical, psychosocial, and spiritual suffering, is needed. The transition to hospice care is made when HF is refractory to medical therapy or when the potential harm of treatment outweighs the potential benefits. Nurses are key persons for patients with HF as they may initiate and support palliative and hospice care, focus on delivering patients' goal-directed, well-coordinated care, champion patients' and caregivers' needs, and facilitate optimal QOL. Despite the inclusion of palliative and hospice care for HF patients in published guidelines, health care providers are frequently unfamiliar with palliative and hospice care and the needs of HF patients and their families. Therefore, this paper addresses the nurses' role in determining for whom, and when palliative and hospice care is appropriate; where and how palliative and hospice care should be provided; and the communication needs of patients and their families regarding referral to hospice, emergencies, implantable cardioverter-defibrillator therapy, ventricular assist devices, and continuous intravenous inotropic or vasoactive support at the end-of-life.

Keywords: palliative care, hospice care, end of life care, palliative care nursing, hospice care nursing, heart failure, heart failure therapy

Introduction

Patients with chronic heart failure (HF) suffer from quality-of-life (QOL) concerns and numerous symptoms, and, thus, are in need of a palliative care (PC) approach early and throughout the disease trajectory and hospice care (HC) at the end-of-life (EOL).¹⁻¹⁰ However, despite the inclusion of PC and HC for HF patients in published guidelines,¹¹⁻¹³ physicians¹² and nurses¹³ are frequently unfamiliar with the care and needs of HF patients. Therefore, the purpose of this article is to:

1. address the PC through HC continuum and for whom, when, and where PC and HC is appropriate;
2. describe critical components of PC and HC; and
3. discuss the communication and decision-making needs of patients and their families during PC and HC.

PC is a multidisciplinary, patient-centered approach that includes the family and may be provided in any care setting. Care focuses on the improvement of patients' and families' QOL through symptom prevention and management; the relief of physical, psychosocial, and spiritual suffering; and the provision of a support system, for

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patients until death and for grieving family members after the patients' death.^{4,14} HC is EOL care when patients' HF is refractory to life-prolonging medical therapy and the patient has a prognosis of 6 months or less. Life-prolonging care is discontinued, and the care focus is now on preparation of the patient and family for death.

Care coordination

Patients and families require care that is highly coordinated and patient and family centric to optimize and integrate the most appropriate service delivery¹⁵ across all care settings.¹⁶ Organized and coordinated service planning and care delivery should include:

1. educating staff as to their role in the coordination of services;
2. ensuring adequate staff to support coordination activities;
3. facilitating timely communication across service providers through an interoperable information technology platform; and
4. supporting patient and caregivers with effective communication that understands and works well with and for them.¹⁷

As HF patients rarely thought about HF as a terminal illness failure¹⁸ and 68% of patients' spouses (n=38) could not provide a definition of PC,¹⁹ they may need education about the aims and benefits of PC. High-quality PC, when introduced early, can promote a better understanding of the disease and illness trajectory, thus enabling patients to make more informed decisions with their families prior to the EOL.²⁰ By championing patients' needs, clinicians can ensure that there is clear communication and improve the multidisciplinary team's collaboration to provide well-coordinated, patient-focused care.²¹

Critical components of PC

Critical components of effective HF PC include care that is an integrated complement to life-prolonging HF care^{10,22} with a key health care provider coordinating the care; holistic and regular assessment, and monitoring;²³ patient-centered, goal-defined²⁰ care plans that include planning for the future;^{10,22} and an advanced directive that is reviewed regularly by the care team, patient, and caregivers. Care must be coordinated across care settings.¹ Regular assessment and review of the caregivers' needs and caregiver support^{10,22} that includes respite and bereavement care are also important.²⁴

Care planning

From the time of diagnosis, goals of care and care preferences must be discussed and established with the patient and family. Planning should take place before the patient becomes too incapacitated to participate in decision-making and consider such issues as how to respond to sudden HF exacerbations, progression of comorbid conditions, and cardiac arrest.^{22,25} If patients prefer not to participate in decision-making, then they should be asked to appoint someone to make decisions on their behalf, and the process, decision, and details regarding the appointee should be documented. The care plans must be reviewed regularly, especially during periods of significant clinical change (hospitalization, additional comorbidities, disease progression).^{16,25,26}

Care preferences are related to knowledge and understanding deficits,^{17,27} health-literacy,²⁸ educational level,²² time constraints,^{26,27} and difficulties in navigating and accessing health and social care support.^{17,22,27} Given that care preferences are rarely discussed on hospital admission,³ clinicians must engage patients in conversations about what will happen during and following the hospital admission. In general, patients want more information than is provided to them by clinicians about their disease.²⁹ As the majority of older HF patients demonstrate poor health-literacy, especially with respect to HF,³⁰ attention is needed to provide low health-literacy appropriate teaching, decision-making, and care. Further, attention to ameliorating the time constraints and navigation difficulties is needed.

Advance directives

Advance directives are legal documents created by patients and shared with the family and clinicians that identify desired or undesired treatments in the event an individual becomes incapacitated and incapable of making or communicating decisions about care preferences. The individual identified by the patient to serve as their spokesperson is documented. Thus, patients are assured that their health-care team knows their care preferences and spokesperson.

Disease Specific Advance Care Planning, a facilitated advanced planning intervention that emphasized condition-specific treatment, resulted in greater understanding of patient goals and higher rates of advance directives completion for those who participated in the intervention versus those who did not (94.3% versus 24.8%; $P < 0.001$). Of patients who died by the end of the study period (n=286, 15%), intervention participants were more

likely to have used hospice than control participants (56% versus 37%; $P=0.002$).¹⁷

During discussions about care preferences, prognosis, resuscitation (cardiopulmonary resuscitation [CPR], advanced life support), and circumstances for discontinuing invasive therapy such as inotropic infusions or cardiac devices (cardiac resynchronization, ventricular assist) should be carefully and objectively explored with both patients and families.^{14,22,31} Unfortunately, only 43% of patients report that their physician discussed their care preferences with them.³²

Resuscitation

Discussions about resuscitation care preferences are important to ensure patient-centered care. In patients with severe HF, 8% were unsure about resuscitation, 23% preferred no resuscitation, and 19% changed their preference after 6 months. However, during the last month of life in patients older than 80 years who died within 1 year of their enrollment hospitalization, 60% in hospital and 80% out of hospital preferred not to be resuscitated. At the time of death, 80% of these elderly patients had a “do not resuscitate” order and 60% had an order to withhold a ventilator.³³ Therefore, clinicians must discuss and document the patients’ wishes for resuscitation initially and periodically throughout the patients’ care.

Cardiac resynchronization therapy

Patients receiving cardiac resynchronization therapy require discussions about care preferences for deactivation of the implantable cardioverter-defibrillator (ICD) in the event they develop end-stage disease. As part of the discussion, clinicians need to ensure that patients and families understand that turning off the ICD means that the device will no longer provide lifesaving intervention if a fatal heart rhythm occurs and that immediate death and pain will not be caused.^{14,34}

In the largest American study looking at 105 symptomatic HF patients receiving cardiac resynchronization therapy and their ICD care preferences, recipients of ICDs (66%) were more confident about the device’s lifesaving capacity than patients who did not have one.³⁵ Not surprisingly then, patients with ICDs were hesitant to have their devices deactivated if they developed end-stage disease. Also, patients preferred the ICD to remain active even if they were dying of cancer (70%) or having daily shocks (55%), and none of them inactivated the ICD if suffering from dyspnea at rest.³⁵

Clinicians infrequently discuss ICD deactivation with patients and most devices remain active, continuing to shock until death.^{14,30,36} The concurrent Working to Improve diScussions about DefibrillatOr Management, a six-center trial, reports 27% of patients received shocks at the EOL with the experience being painful, traumatic, and distressing for patients and families.³⁷ Therefore, particular care should be taken to ensure that discussions of ICD deactivation occur early, with the patient and family together while the patient is still capable of participating.

Ventricular assist devices

Care preferences regarding ventricular assist devices (VADs) need to be addressed before implantation of the VAD and revisited with any significant change in the patients’ status that changes the goals of support.³⁸ Patients need to understand that the VAD may prolong the dying process and continue to work even after the patient is clinically brain dead.^{25,39} Thus, the establishment of the patients’ advance directives and the documented discussions that outline the conditions under which the patients desire the device to be withdrawn is critical to ensure the patients’ wishes are met.^{39–41}

Discussions need to include PC and EOL care wishes relative to the VAD particularly for patients with VAD support for long periods of time or patients who are living with unpleasant symptoms caused by complications of VAD support.³⁸ Of 20 patients with a VAD who actively participated in VAD care preference discussions, retrospective review showed that 17 chose to actively withdraw support and three chose to wait until they lost consciousness before having the device withdrawn. The time from the decision to withdraw the VAD was less than 1 day–2 weeks and from withdrawal to death was less than 20 minutes. Therefore, patients need to understand the immediacy of death following VAD withdrawal, queried about the conditions under which they would desire the device be withdrawn, and the VAD care preferences should be documented to ensure the patients’ wishes are met.^{39–41}

Sudden cardiac death and resuscitation

While the focus of advanced therapy is to optimize function and prolong life, the life-limiting nature of HF and increased risk of associated sudden cardiac death (SCD) should be acknowledged and discussed at the time of diagnosis as part of the initial education offered to HF patients and families.^{14,22} Patients with HF do not perceive

the life-limiting nature of HF.^{18,42} Thus, patients and family members need explicit communication about the HF disease trajectory, the life-limiting nature of HF,¹³ the prognosis, and the possibility of SCD despite optimal care.⁴³ Providing HF patients and families a warning that death may come abruptly or with chronic illness helps eliminate surprise from future communications when the patient's health condition suddenly deteriorates or he/she is at the EOL.⁴⁴ In addition to helping them prepare for the worst should they die sooner than expected, knowledge of the life-limiting nature of HF may also assist patients and their families to better adhere to the PC treatment plan: medication,^{14,17,22} diet,¹⁴ and exercise.^{14,25}

Communication should begin with the clinician asking patients about their understanding of HF, and determining the patient and family desired information. Then, the clinician provides small chunks of information, and seeks patient and family feedback to elicit understanding.⁴⁵ The discussions need to be regular and repeated, particularly at times of change, to ensure understanding and patient/family satisfaction.⁴⁶ Developing sensitive communication skills is an essential component for effective discussions of PC and EOL issues.²⁶

All HF patients and their families should create a plan to manage potential SCD, including those with life-prolonging interventions such as ICDs.^{22,45} Patients report wanting their families to know what to do in an emergency, and families commonly express the need to know how to respond in a cardiac emergency. Families report that the learning need about emergencies is often unmet by health-care professionals.⁴⁶⁻⁴⁸ A discussion involving patients and families about the patients' wishes regarding resuscitation can include information about the effectiveness of resuscitation and the associated sequelae.⁴⁹ The majority of family members of patients at risk for SCD can successfully learn CPR, are not burdened by responsibility or guilt, and utilize CPR techniques appropriately when the need arises.^{50,51}

For those patients who choose to allow for a natural death, their family caregivers need to be told what to do when death occurs outside the hospital. The caregivers should be instructed to contact a health-care provider who has a relationship with the patient not 911, inform the provider of the patient's preference to not attempt resuscitation, and discuss the need of the provider to certify the cause of death.

The importance of patients' trust in health professionals and their belief that they will receive good care through to death cannot be overstated.⁵² In addition, emotional and

spiritual support that includes the assessment of family stresses and financial resources and the identification of coping strategies and roles²² needs to be provided to both the patient and caregivers. To provide optimal PC, clinicians need to be knowledgeable about the patients' and caregivers' needs regarding HF self-management.

Clinicians' role in determining when and for whom PC and HC is appropriate

PC needs to be considered and initiated at the time the patient is diagnosed with HF.⁵³ PC needs to be incrementally increased as the HF progresses, until, eventually, life-prolonging care is discontinued and the transition to HC is made.

Generally, patients in New York Heart Association classes I-III HF are appropriate patients for whom PC may be offered. Thus, patients with mild HF (no/slight physical activity limitation) to patients with moderate HF (marked physical activity limitation [fatigue, palpitation, or dyspnea]) may be suitable for PC.

If PC is provided by a separate, distinct service, early consultation is recommended as PC consultations generally occur too late (median time from PC consultations to death is 21 days [3-125]).¹⁷ Timely PC consultations result in increased referrals to hospice, integration of broader PC services,¹⁷ and earlier referrals to HC.⁵⁴ Also, early consultation may reduce symptom burden and depression while enhancing QOL.⁵⁵

Key components of PC – QOL and symptom management

For patients, living with HF involves many losses, changes, and challenges.⁵⁶ HF involves managing the illness (organizing medications and other care) and maintaining the illness (partitioning activities into manageable chunks plus strict timing and organization of activities).⁵⁷ Patients experience significant fatigue,⁵⁸ and difficulties with managing and maintaining daily activities that result in a need to rely on others. As a result, many experience a loss of activities (social gatherings/work) and an associated disruption of their self-image. The recognition that help from others is required to manage HF⁵⁶ results in feelings of loneliness, isolation, and being a burden.⁵² Thus, helping patients to manage symptoms through ongoing education, interventions, and reevaluation; optimizing their social activities and feelings of self-worth through actual/virtual and in-/out-of-home events; and facilitating the infrastructure needed to live with HF through referrals to and consultations with auxiliary members of the health-care team⁵⁷ are critical to optimizing QOL. However,

additional data are needed to optimize QOL and symptom management.¹

The content, structure, and timing of PC aimed at improving the QOL for both patients and families were addressed using in-depth interviews of 33 adult outpatients with symptomatic HF and 20 of their family caregivers.³⁶ They described the needed content as symptoms alleviation and adjustment to limitations and the future illness course.⁵⁸ Patients and family caregivers said that services should be structured using a team approach by clinicians familiar with the patient and that family caregivers should be involved in the PC to enhance communication and coordinate care. PC services should begin at the beginning of illness and continue throughout the illness.⁵⁹ Thus, clinical care in advanced HF needs to focus on improving communication, self-care, and advanced care planning,^{29,36,41,59} while considering the particular health beliefs, values, and coping mechanisms.²⁶

Relief from suffering

Physical and psychosocial suffering

Common symptoms associated with advanced HF and recommendations for symptom management are provided in Tables 1 and 2.

In addition to physical symptoms, HF patients are frustrated by living with HF and describe the need to talk about the:

1. disease/symptoms;^{23,93}
2. necessity to be on medication;
3. decisions regarding advanced directives and HC;⁵⁷ and
4. need for information and better communication from their health-care team.^{23,93}

Patients' emotional symptoms include hopelessness,⁹⁴ sadness, and feeling imprisoned by their illness.⁹³ Further, as comorbid depression is common in both patients and caregivers, assessment and treatment of depression is critical for both.¹⁰ Patients also fear pain, dying too young, and

agreeing to a treatment they did not want at the end. Patients with HF need assistance to live with inadequate information, uncertainty, anxiety, psychological morbidity, and the inability to plan appropriately.⁹

Not being a burden to their family is extremely important to patients with HF (43.5%), yet only 22% are completely satisfied that they are not a burden.⁹⁵ As patients with HF fear being a burden as they deteriorate and become more dependent,⁹³ attention to the fear, dependence,⁵² and personal and home adaptations is critical.

The Needs Assessment Tool: Progressive Disease-Heart Failure is an easy to administer, comprehensive, and relevant tool to objectively determine HF patient needs.⁹⁶ Finally, HF patients' experience and needs-based discussions linked to patients' values must occur over time, ideally, and may require revisiting at turning points in the patients' disease trajectory. Understanding the experiences and needs of HF patients is critical to informing patient-centered PC as some patients have unmet PC needs.²³

Spiritual suffering

Spiritual concerns are important for many patients, both early and late in the illness progression. The spiritual needs for patients with HF; the need for love, belonging, hope, coping, meaning,⁹⁴ and purpose;⁹⁶ and the need for attention to their faith, beliefs, existential issues,⁹⁷ and loneliness may exist whether or not they have religious beliefs. Unfortunately, only a minority of patients report that their physician discussed their religious beliefs (31%).³² Importantly, clinicians must address the spiritual needs and concerns of patients.

Patients describe a three-step (past, present, and future oriented) process where spirituality contributed to their adjustment to advanced HF: 1) the development of regret regarding behaviors and lifestyles; 2) the search for meaning within the experience of HF; and 3) the search for hope and reclaiming of optimism.⁹⁴ Patients' hope may be simply about the ability to go for a walk, get out of the house, or gain some independence while others hope for a longer life or time to participate in an important event, like a wedding or graduation.⁹⁸ Hopelessness may be present alongside feelings of hope, but for some, hopelessness is a feeling that their lives are finished.⁹³ Thus, clinicians must work to facilitate patients' adjustment to HF by facilitating the resolution of their regret; their understanding about the meaning and purpose for their life, and the search for hope; and the reclaiming of optimism.

The balancing of hopes and fears is common to PC and HC.⁵² Patient-centered care with a focus on the patient as a

Table 1 Common symptoms associated with advanced HF

Symptom class	Examples
Physical	Dyspnea, pain, edema, fatigue, exercise intolerance, anorexia, nausea, constipation, gout, pruritus, pain, muscle cramps
Psychological	Panic attacks, fear, anxiety, depression, cognitive impairment, loss of confidence, insomnia, feelings of uselessness or hopelessness, feelings of social isolation, feeling a burden
Social/functional	Falls, trouble walking, incontinence, loss of independence in performing activities of daily living

Note: Data from,^{1,13,14,22,30,43,47,57}

Abbreviation: HF, heart failure.

Table 2 Symptom management in PC

Physical symptoms	Treatment
Poor 6-minute walk distance	Angiotensin-converting enzyme inhibitors ⁶⁰ Angiotensin-converting enzyme inhibitors in patients with NYHA functional classes II–III HF ⁶¹ Caffeine ⁶²
Exercise intolerance, exertion, fatigue	Angiotensin-converting enzyme inhibitors ^{61,63} Continuous positive airway pressure ⁶⁴ Loop diuretics ⁶⁵ Fluid and sodium intake restriction ⁶⁶ Caffeine ⁶² Treatment of secondary causes such as anemia (with erythropoietin ⁷³), infection, sleep apnea, ^{98,143} or depression ²² Enhance self-assessed control over their HF ⁶⁷ Exercise ^{68,69,144} Inspiratory respiratory muscle training ^{70–72} Stimulants ¹⁴³ Hawthorne extract ¹³⁷ Cardiac resynchronization therapy ⁷⁴ Destination left ventricular assist devices ⁷⁵
Muscle weakness	Specific thigh muscle training ⁷⁶
Dyspnea/orthopnea/edema	Angiotensin-converting enzyme inhibitors in patients with NYHA functional classes II–III HF ⁶¹ Aldosterone blockade with monitoring of patient-reported symptoms to assess individual benefit ⁷⁷ Loop diuretics ⁶⁵ with or without thiazides ¹²⁹ in patients with LVSD ⁷⁸ Aquapheresis (if diuretic resistant) ¹³³ Nitrates ¹²⁰ or low-dose opioids ^{25,130,131} Opioids in NYHA functional classes II–III patients ^{80–82} Nitroglycerine, intravenous for decompensated HF ⁷⁹ Inotropes ¹³² Fluid and sodium intake restriction ⁶⁶ Breathing ¹³⁴ and inspiratory respiratory muscle training ^{75–77} Specific thigh muscle ⁷⁶ and exercise training ¹³⁵ Walking aids ¹³⁴ Hawthorn extract ¹³⁶ Oxygen (without hypoxia) ¹³⁷ Hand held fan ¹⁵⁰
Poor QOL	Beta-blockers ^{83,84} Nocturnal oxygen supplementation in HF patients with Cheynes–Stokes respiration ⁸⁵ Loop diuretics in patients with LVSD ⁷⁸ Exercise ^{68,69} Inotrope infusion therapy ^{86,87} Cardiac resynchronization therapy ⁷⁴ Destination left ventricular assist devices ⁷⁵
Cheyne–Stokes respiration	Continuous positive airway pressure ⁸⁸ Aerobic exercise ⁸⁹
Intermittent pain	Intermittent opioids (morphine, codeine [and possibly hydromorphone]) – only for intermittent use, ⁷⁹ plus stimulant laxative prescription ¹ Nitrates, beta-blockers, calcium channel blockers, ranolazine, and coronary revascularization for anginal pain ^{138,139} Acupuncture ¹⁴⁰ Exercise training ¹⁴¹ Music ¹⁴²
Osteoarthritis or chronic musculoskeletal pain	Combination of muscle-strengthening exercises, assistive devices/modalities (heat, cold, ultrasound), intra-articular joint injection, and around-the-clock Intermittent opioids (morphine, codeine [and possibly hydromorphone]) – only for intermittent use, ⁷⁹ plus stimulant laxative prescription ¹ Opioids and bisphosphonates for bone pain ¹³⁸

(Continued)

Table 2 (Continued)

Psychological/social/functional symptoms	Treatment
Emotional function, sense of control	Continuous positive airway pressure ⁶⁴ Enhance self-assessed control over their HF ⁶⁷
Anxiety	Increase spousal sense of control ⁹⁰ Mindfulness support group and HF education ⁹¹ Benzodiazepines ¹
Social function and vitality	Continuous positive airway pressure ⁶⁴
Depression	Selective serotonin reuptake inhibitors – in patients with renal impairment monitor serum sodium ⁹² Serotonin–norepinephrine reuptake inhibitors and tricyclic antidepressants ¹⁴⁵ Psychological interventions such as cognitive behavioral therapy, counseling, or supportive therapy ¹⁴⁶ Mindfulness support group and HF education ⁹¹ Exercise ¹⁴⁷

Abbreviations: PC, palliative care; NYHA, New York Heart Association; HF, heart failure; LVSD, left ventricular systolic dysfunction; QOL, quality-of-life.

whole person with emotional, social, and spiritual needs in addition to physical concerns and symptom management could demonstrate the holistic caring approach patients and families seek.

Transition

The transition to HC or EOL care is made when the patient wishes or when the potential harm of treatment outweighs the potential benefits. However, the transition from the independence of PC to the dependence of HC is not a simple linear process for patients with HF.⁵² Identification of patients nearing the EOL should be made in collaboration with clinicians experienced in the care of patients with HF, when possible, and coordinated with the patients' primary care physician.³²

Hospice care

Prognostication in HF is difficult.¹ Guidelines for HF care do not specifically address when to refer end-stage HF patients for HC or EOL care,⁹⁹ and the National Hospice Organization prognostic criteria for determining hospice eligibility in HF patients are not useful in predicting 6-month prognosis.¹⁰⁰ Further, the HF trajectory is unpredictable with varying periods of remission and exacerbation,^{101,102} and there is no typical trajectory.¹⁰³ Thus, when to refer patients to HC may be difficult to determine. Generally, however, patients in stage D/New York Heart Association class IV HF and patients with severe HF who are unable to do any physical activity without discomfort and/or experience symptoms at rest may be considered for HC. In a small study of 282 patients older than 70 years (mean age 79 years), 43 patients died within 6 months of study enrollment and were assessed for common clinical characteristics.

Serum blood urea nitrogen ≥ 30 mg/dL (odds ratio [OR] =5.78, 95% confidence interval [CI] =2.65–12.66),

systolic blood pressure < 120 mmHg (OR =4.81, 95% CI =1.94–11.91), peripheral arterial disease (OR =3.09, 95% CI =1.26–7.58), and serum sodium < 135 mEq/L (OR =2.27, 95% CI =0.98–5.27) were independent clinical correlates of 6-month mortality.¹⁰⁴ Thus, patients with these four clinical characteristics may represent HF patients for whom referral HC might be appropriate.

Prognosis/mortality

Breathlessness was the most common symptom (men 90%, women 86%) of 21 symptoms documented in the charts of late-stage HF patients¹³ while in the last 6 months of life, the two symptoms most commonly reported by family members were dyspnea (61%) and pain (78%).^{43,105} In addition, low mood was reported by 59%, sleeplessness by 45%, anorexia by 43%, and confusion by 40%.⁴³ The significant predictors for HC and in-hospital mortality are provided in Table 3.

Single-item predictors such as the 6-minute walk test,¹⁰⁹ B-type natriuretic peptide,¹¹⁰ and creatinine levels¹¹¹ may be clinically helpful. Prognostic factors, tools, and models developed for HF may be useful too. Ongoing assessments of patients at high likelihood of death at 1 year may be assessed by using a prognostic, multivariable model (HF Survival Score,¹¹² Zugck two-variable model,¹¹³ HF Risk Scoring System,¹¹⁴ HF Risk Calculator,¹¹⁵ Digitalis Investigation Group model,¹¹⁶ Seattle HF model,¹¹⁷ Munich score,¹¹⁸ and the Barcelona Bio-HF Risk Calculator¹¹⁹). However, no reliable and validated tool is available to determine death within 6 months contributing to the difficulty of timely referrals (Table 4).

The HF Risk Scoring System¹¹⁴ is a 30-day mortality risk predictor and the Palliative Performance Scale, a generic tool that assesses ambulation, activity and extent of disease, self-care, intake, and consciousness level,¹²⁰

Table 3 Predictors of need for hospice care and in-hospital mortality

Predictors	Need for HC ^{14,106}	In-hospital mortality ^{107,108}
Age: >70 years; per 10-year increase		X
African American		X
Heart rate: per 10 bpm increase between 65 bpm and 110 bpm		X
Systolic blood pressure: ≤124 mmHg; per 10-mmHg increase up to 160 mmHg		X
Diastolic blood pressure: per 10-mmHg increase up to 100 mmHg		X
Presence of edema	X	
General deterioration – orthopnea, nocturia, dyspnea	X	
Weight increases and fails to respond to increased diuretics	X	
Sodium: per 3-mEq/L decrease, above or below 140 mEq		X
Low sodium	X<134 mEq/L	X<136 mEq/L
Serum creatinine: per 0.3-mg/dL increase up to 3.5 mg/dL	X>2 mg/dL	X>1.4 mg/dL
BUN: >37 mg/dL		X
Low hemoglobin		X
Severe limitations, NYHA IV	X	
Moderate disability requiring considerable assistance and frequent care (Karnofsky score ≤50%)	X	
>3 hospital admissions/year	X	
>3 severe HF exacerbations/year	X	
Pain		
Ejection fraction improvement at 6 months		
Low cardiac output	X	
Cause of admission: HF		X
ACE inhibitor or beta-blocker at admission		X
Patient mentions EOL approaching	X	
Presence of cancer		X
Smoker within past year		X
Hyperlipidemia, liver disease, chronic obstructive pulmonary disease, peripheral vascular disease, left ventricular systolic dysfunction, or no known HF before current admission		X
Previous cerebrovascular accident/transient ischemic attack	X	X
Diabetes mellitus		
Chronic renal insufficiency		
Low cutaneous flow		

Abbreviations: HC, hospice care; BUN, blood urea nitrogen; NYHA, New York Heart Association; IV, intravenous; HF, heart failure; ACE, angiotensin-converting enzyme; EOL, end-of-life.

may predict risk of death within 1–145 days. Both were correlated with 1 year death prediction.¹²¹ However, nurses' prognostic predictions for hospitalized HF patients were better than either prognostic model.¹²² HC may be provided in the home, a long-term care center, or a special hospice unit²⁰ and is designed to provide symptom relief, comfort, and support for patients and their families. In a long-term care center, families communicated with many health-care providers, but most often worked through the nurse when problems arose or decisions about care needed to be made.¹²³

Key components of quality HC include the provision of easy access to coordinated care,¹⁵ support for emotional and spiritual concerns, adequate pain and symptom management, and avoidance of the inappropriate prolongation of death. Patients' perceived sense of control and strengthened relationships with the loved ones are critical to optimal HC.^{46,94,124} Patients acknowledge endings and losses, the need to manage

regrets about previous behavior and uncertainty,⁹⁵ and the desire for good care at the EOL.⁵³

Early referrals to HC are preferable to late referrals as late referrals are associated with lower overall family satisfaction, hospice services' satisfaction, and confidence in participating in patient care at home. Further, later referrals yield more unmet needs, a lack of awareness about what to expect at the time of death, and concerns about care coordination.¹²⁵ In half of all cases of late referral, family members reported that physicians were a barrier to earlier hospice referral.¹⁰²

Implantable cardioverter devices

The maintained activation of the ICD when transitioning to HC may be an issue. A survey of 414 hospices reported that only 20% of hospices assessed patients for the presence of an ICD on admission with only 10% of them having a deactivation policy.¹²⁶ Of the patients with active devices, 42% had the shocking function turned off once they

Table 4 One-year death prediction risk models in chronological order

Factor	HF survival score ¹¹²	Zugck two-variable model ¹¹³	HF risk calculator factors ¹¹⁴ (in order of predictive strength)	HF risk scoring system ^{114,@}	Digitalis investigation group model ¹¹⁶	Seattle HF model ¹¹⁷	Munich score ¹¹⁸	Barcelona Bio-HF risk calculator ¹¹⁹
Age			X	X	X	X		X
Lower EF	X		X		X	X		X
NYHA class		X	X		X	X		X
Serum creatinine			X		X			
Diabetes			X					
Not prescribed beta-blocker			X		X [^]			X
Lower systolic BP			X	X	X			
Lower body mass			X					
Time since diagnosis			X					
Current smoker			X					
Chronic obstructive pulmonary disease			X	X				
Male			X			X		X
Not prescribed ACE-inhibitor or angiotensin-receptor blockers			X		X [^]			X
Resting heart rate	X							
Mean resting blood pressure	X						X [#]	
Intraventricular conduction delay	X				X	X		
Maximal oxygen consumption	X							
Serum sodium	X	X ^{\$}		X		X		X
Pulmonary capillary wedge pressure	X							
6-minute walk test		X						
Respiratory rate				X				
BUN				X				
Estimated glomerular filtration								
Comorbid conditions: cerebrovascular disease, dementia, cirrhosis, cancer, anemia				X				X
Cardiothoracic ratio >50%					X			
Clinical signs/symptoms					X			
Body mass index					X			
Nitrate use					X [*]			
If diabetes, cause of HF					X [^]			
Cause of HF							X	
Diuretic dose					X			
Anemia					X			X
Lymphocytes (%)					X			
Uric acid					X			
Total cholesterol					X			
Use of devices					X			
Left ventricular end-diastolic diameter							X	

(Continued)

Table 4 (Continued)

Factor	HF survival score ¹²	Zugck two-variable model ¹³	HF risk factors ¹⁴ (in order of predictive strength)	HF risk scoring system ¹⁴ @	Digitalis investigation group model ¹¹⁶	Seattle HF model ¹¹⁷	Munich score ¹¹⁸	Barcelona Bio-HF risk calculator ¹¹⁹
Maximum workload							X	
Worsening of fractional shortening (%)							X	
Hemoglobin								X
Statin								X
High sensitivity troponin T								X
ST2								X
NT-proBNP levels								X

Notes: *Weight only; ^medication use; †systolic blood pressure; @30-day and 1-year predictions; ‡either intraventricular conduction delay or pulmonary capillary wedge pressure is used in the Zugck two-variable model.
Abbreviations: HF, heart failure; EF, ejection fraction; NYHA, New York Heart Association; BP, blood pressure; ACE, angiotensin-converting enzyme; BUN, blood urea nitrogen; NT-proBNP, N-terminal of the prohormone brain natriuretic peptide.

transitioned to HC.¹²⁶ However, as patients were hesitant to have their devices deactivated if they developed end-stage disease and none would inactivate the ICD if suffering from dyspnea at rest,³⁵ consideration of hospice policies and patients' ICD care preferences need to be considered when referring patients to hospice.

Preferences about death and dying

As HC is focused on providing a good death,¹¹⁷ attention to how patients define a good death is warranted.¹²⁷ HF patients described the best death as a death that is peaceful and without panic. Further, the preference is for dying with dignity, dying without suffering, and dying in institutional settings for the majority of older participants.^{5,117}

Although many patients were willing to talk about their feelings, a significant number expressed ambivalence or reservation about answering questions related to death.⁵⁶ Some patients were disappointed that the health-care team did not discuss dying with them⁹⁵ while some older HF patients did not want an open acknowledgment of the imminence of dying and death.¹¹⁷ In addition, as only 25% of patients had discussed their preference with their provider,¹¹⁷ it is incumbent upon clinicians to initiate the discussion about the patients' definition of a good death and their treatment preferences including HC, to document the findings, and to revisit the issue periodically.

Inotropic infusion support

Patients with end-stage HF refractory to standard treatment may be hospitalized or discharged home with inotropic intermittent or continuous-infusion support^{14,25} to improve dyspnea and increase exercise capacity.²² In a retrospective study of end-stage patients given continuous-infusion milrinone or dobutamine, the 6-month and 1-year survival rates were 58% and 44%, respectively.¹²⁸ Thus, a documented discussion between the patient, family, and health-care team should determine the patients' wishes about when not to increase the infusion rate and when to discontinue the inotropic therapy.

Dyspnea

Class I recommendations for the management of dyspnea include loop diuretics with or without thiazides,¹²⁹ nitrates,¹²⁰ or low-dose opioids.^{25,130,131} Class IIa recommendations include inotropes, aquapheresis (if diuretic resistant),^{132,133} walking aids,¹³⁴ breathing¹³⁴ and exercise training,¹³⁵ and Hawthorn extract.¹³⁶ A class IIB recommendation is oxygen (without hypoxia).¹³⁷

Pain

Class I recommendations for the management of pain include opioids and bisphosphonates for bone pain,¹³⁸ and nitrates, beta-blockers, calcium channel blockers, ranolazine, and coronary revascularization for anginal pain.^{138,139} Class IIb recommendations include acupuncture,¹⁴⁰ exercise training,¹⁴¹ and music.¹⁴²

Fatigue

There are no Class I recommendations for the treatment of fatigue. Class IIa recommendations include treatment of secondary causes such as anemia, infection, or sleep apnea;^{98,143} the use of stimulants;¹⁴³ exercise training;¹⁴⁴ and Hawthorne extract.¹³⁷

Depression

The Class I recommendation for the treatment of depression is the use of selective serotonin reuptake inhibitors, serotonin–norepinephrine reuptake inhibitors, and tricyclic antidepressants.¹⁴⁵ Class IIa recommendations include psychological interventions such as cognitive behavioral therapy, counseling, or supportive therapy¹⁴⁶ while exercise¹⁴⁷ is indicated as a Class IIb recommendation.

Caregivers' needs

Caregivers' needs relate to two primary domains of support: 1) support to enable them to provide care and 2) support for themselves. Caregivers' perspectives of key support needed during provision of EOL care at home describe 14 domains of needed support: 1) having a named support contact; 2) managing the patient's symptoms and medicines;⁹ 3) supporting with equipment knowledge; 4) providing personal care; 5) understanding the illness; 6) understanding the dying process; 7) talking with the patient about the illness; 8) supporting at the time of death; 9) providing caregiver respite support; addressing 10) physical health concerns, 11) financial issues, and 12) work issues; and providing 13) practical and 14) emotional support.¹⁴⁸ Specifically, caregivers desired help communicating with the person for whom they cared, especially about dying and death.⁴⁷ Caregivers also described needs about how to cope with uncertainty, anxiety, and significant psychological morbidity.⁹ In addition, they voiced their own spiritual needs.⁹ Patients and caregivers were generally reluctant to raise spiritual issues, but many were able to talk about such needs.¹⁴⁹

The brief Carer Support Needs Assessment Tool is a valid, evidence-based, 40-item screening tool for use in practice to

objectively determine the needs of HF caregivers that require further detailed assessment.¹⁴⁸ The use of this tool may be helpful to identifying caregivers' needs.

Conclusion

Comprehensive HF care should integrate PC throughout the course of disease management and integrate HC at the EOL. Clinicians, in collaboration with a skilled multidisciplinary team, must advocate and provide for PC earlier rather than later in the HF disease trajectory addressing the humanistic and holistic needs of patients and families living and dying with HF. Care should be patient- and family-centered, and focused on planning for an uncertain future including completion of an advance directive, prevention and management of physical, psychosocial, and spiritual suffering; optimizing overall function and QOL; and achieving a satisfactory level of comfort.

Partnership with patients and families in managing their disease process is crucial. By empowering patients and families through the sharing of knowledge and support, effective communication and timely, honest feedback, patients and families are better able to maintain dignity, hope, and a level of optimism as they face the challenges ahead of them.

Disclosure

The authors report no conflicts of interest in this work.

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