

Palliative care in patients with heart failure



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ABSTRACT

Despite advances in cardiac therapy, heart failure (HF) remains a progressive, highly symptomatic, and deadly disease that places great demands on patients, caregivers, and healthcare systems. Palliative care is a multidisciplinary approach to care that focuses on communication, shared decision making, and advance care planning; provides relief from pain and other distressing symptoms; integrates psychological and spiritual aspects of care; and offers a support system to help families cope during illness and bereavement. Palliative care has applications across the stages of heart failure, including early in the course of illness, often in conjunction with other therapies that are intended to prolong life. However, the incorporation of palliative care into the management of heart failure has been suboptimal for several reasons: uncertainty in the disease trajectory, failure to reward communication between healthcare providers and patients, siloed care, lack of knowledge, overlay of comorbidity and frailty, life saving devices with complex trade-offs, and a limited evidence base. This review will summarize the current literature on the emerging role of palliative care in patients with heart failure and the challenges and opportunities for its integration into routine care. It will discuss current initiatives and future directions of the collaborative relationship between the palliative care and heart failure disciplines.

Introduction

Heart failure is a syndrome of cardiac dysfunction characterized by dyspnea, fatigue, and fluid retention.¹ Once patients develop chronic symptomatic heart failure, the disease often dominates their overall health and medical care. Although heart failure is a syndrome that represents diverse underlying pathophysiology and affects a broad spectrum of the population, it is mostly a disease of older patients with serious comorbidities.

The field of heart failure, after a long period of relatively stagnant treatment options, has entered a new era, with the development of new drugs, monitoring capabilities, and device therapies. However, these advances rarely cure the disease and are often available to only a minority of patients. As such, heart failure remains a worldwide epidemic.²⁻⁵ Morbidity is high, hospital admission is common, median survival is less than five years, and the disease places great demands on patients, caregivers, and healthcare systems.⁶

Palliative care is a multidisciplinary approach to care that focuses on quality of life and a good death. Although palliative care is highly relevant in patients with heart failure, its application in this patient population has been suboptimal.⁷⁻¹⁰ This review will summarize the evidence for palliative care in patients with heart failure, barriers to its integration, and future directions.

Sources and selection criteria

We searched PubMed from 1 January 2010 to 30 September 2015 using the terms “heart failure”, “palliative care”, “quality of life”, “symptom burden”, and “end of life”. MeSH terms common to relevant articles were added to the search terms. Reference lists in the identified articles were also reviewed to identify relevant articles. Literature that was published before 2010 was reviewed and included if it contributed substantially to the fields of heart failure and palliative care. Inclusion of literature published before 2010 was reviewed for impact to the fields of heart failure and palliative care and applicability to current landscape. We also searched the clinicaltrials.gov registry for relevant ongoing trials. Studies were categorized on the basis of themes, including heart failure specific interventions and studies, patient and caregiver preferences related to care, heart failure care at the end of life, and differences in care related to other chronic diseases. Data were then ranked according to their quality, including study type; number of participants; and implications for palliative care in patients with heart failure. Particular attention was given to randomized controlled trials and intervention studies.

Incidence and prevalence

Contemporary registries show that more than half of hospital patients with heart failure in the United States are

over 75 years,¹¹ and the greatest increases in prevalence are projected to occur in those over 85 years of age.¹² The most recent estimates show a worldwide prevalence of 23 million.¹⁻¹⁴ In the US, the prevalence of heart failure will increase by 46% from 2012 to 2030, resulting in an increase from five million to more than eight million Americans living with the disease.¹²

Most contemporary data from developed nations indicate that the incidence of heart failure has plateaued, or even decreased.³⁻¹⁶ This combination of increasing prevalence with stable incidence suggests patients are living longer with symptomatic disease, which has obvious implications for palliative care needs.

Although some patients may die suddenly of cardiac arrhythmia, most patients with symptomatic heart failure die of progressive pump failure associated with severe symptoms preceding death.¹⁷

The economic impact of heart failure is high. Caring for these patients accounts for 1-3% of the total healthcare expenditure in North America,¹⁸ Latin America,¹⁹ and western Europe,²⁰ with most resources being deployed in the last six months of life.²¹

Definition and types of palliative care

The World Health Organization defines palliative care as “an approach that improves the quality of life 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.”²²

Palliative care embodies several principles including relief from pain and other distressing symptoms and the integration of psychological and spiritual aspects of patient care.^{22,23} Initially established for the care of patients with advanced cancer, palliative care has evolved over the past 50 years to become an internationally recognized medical subspecialty, including in the US, Canada, United Kingdom, Ireland, Australia, and New Zealand.

Palliative care versus hospice

Although “palliative care” and “hospice” are often used synonymously, in a few countries, including the US, they have important distinctions. Palliative care is a broadly inclusive term used to describe all forms of care that focuses on quality of life and symptom control over curative therapy, without prognostic restrictions. Hospice is generally defined as a subset of palliative care, reserved for people facing a life limiting illness or injury, and it includes a team oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient’s needs and wishes. Legal definitions of hospice have important implications for defined health insurance benefits.

Primary, secondary, and tertiary palliative care

Various levels of palliative care exist. Primary palliative care refers to the basic skills and proficiencies needed by all providers. Primary care providers and cardiology providers practice primary palliative care to fill the common palliative needs of patients. Secondary palliative care

includes the specialists and organizations that provide consultation and specialty care. Tertiary palliative care refers to the academic medical centers where specialist knowledge for the most difficult cases is practiced, researched, and taught.²⁴ This stratification has obvious applications to provider training and patient triage.

Need for and cost of palliative care

Patients, families, and clinicians have expressed the importance of appropriate care to optimize quality of life as well as to ease the transition to the end of life. However, it is difficult to measure the number of people in need of palliative care. In 2014, WHO and the Worldwide Palliative Care Alliance published the first document to describe the unmet need for palliative care.²⁵ This global atlas estimated that more than 19 million adults worldwide are in need of palliative care at the end of life—about 377 per 100 000 adults (fig 1).²⁵ It is estimated that only one in every 10 people who needs palliative care currently receives it.²⁵

Palliative care has been shown to reduce healthcare spending.^{26,27} An analysis of Medicaid patients in four New York State hospitals reported that patients who received palliative care incurred almost \$7000 (£4955; €6331) less in hospital costs than those who received usual care.²⁸ Inpatient palliative care has been shown to reduce not only length of stay,^{29,30} but also the number of procedures and interventions performed near the end of life.^{31,32} Furthermore, palliative care increases appropriate referrals to hospice, which can in turn decrease costs. A propensity score analysis of Medicare patients estimated that about \$2300 is saved per hospice beneficiary compared with similar patients who do not receive hospice services.³³

Role of palliative care in heart failure

Palliative care has increasingly expanded from its roots in oncology to include chronic progressive illness in general, and heart failure specifically. Although patients with heart failure may experience a similar or worse symptom burden than those with advanced cancer,³⁴ until recently access to palliative and hospice care has been worse and rates of resource use and aggressive treatment higher in patients with heart failure than in those with cancer.^{35,36}

The American Heart Association (AHA) developed guiding principles advocating incorporation of palliative care in patients with cardiovascular disease, including providing patients with access to continuous, coordinated, comprehensive, high quality palliative care given simultaneously with specialist care.³⁷

Because of the progressive, chronic, but unpredictable disease course of heart failure, palliative care can help meet the needs of patients, families, and healthcare providers. For example, patients with heart failure would prefer to die at home, yet most still die in hospital. Consultations with palliative care providers have shown an increase in the likelihood of death at home.³⁸ Furthermore, medical advances have led to increasingly complex medical decision making, particularly around withdrawal or deactivation of device therapy. Palliative care can provide support systems to patients and their families during this time.

DISTRIBUTION OF ADULTS IN NEED OF PALLIATIVE CARE AT THE END OF LIFE, BY DISEASE GROUPS

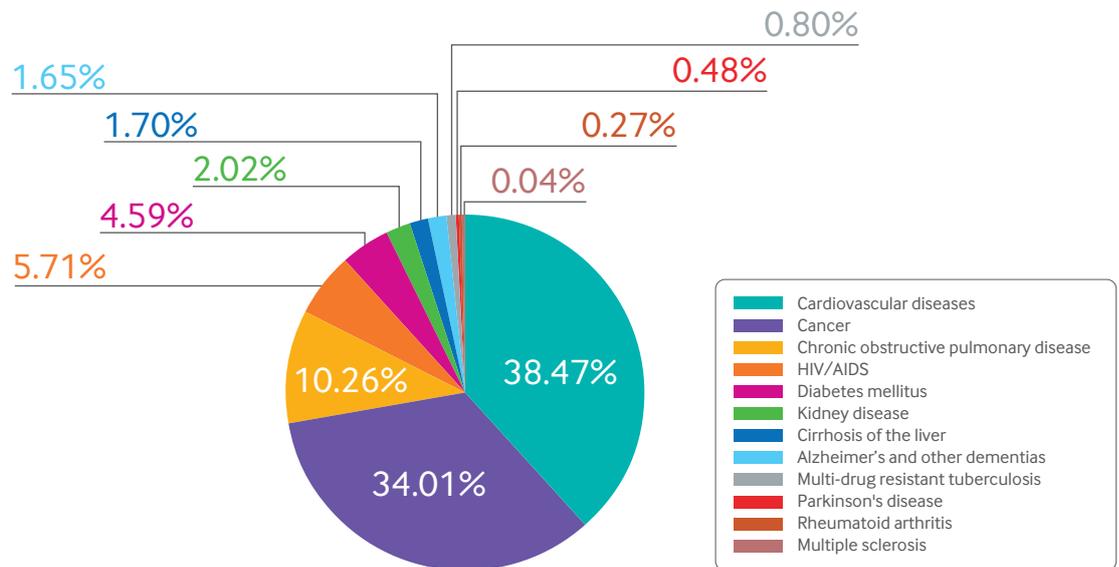


Fig 1 | Distribution of adults in need of palliative care at the end of life by disease. *Adapted, with permission, from the World Health Organization²⁵

Experts and the public are increasingly calling for the expansion of palliative care to patients with heart failure. Many professional and policy organizations have provided recommendations related to palliative care in such patients. In 2012, a scientific statement published by the AHA emphasized the role and integration of palliative care in the treatment of patients with advanced heart failure (fig 2).³⁹ The 2013 ACC (American College of Cardiology)/AHA guidelines on the management of heart failure include a class IB recommendation that palliative and supportive care is effective for patients with symptomatic advanced disease to improve quality of life.¹

A position statement published in 2009 by the palliative care workshop of the Heart Failure Association of the European Society of Cardiology outlines major recommendations that focus on integrating palliative care into a team based approach to comprehensive care. The statement recommends that palliative care is broadly applied rather than being reserved for patients facing imminent death.⁴¹ Subsequently, a section on palliative care was included in the 2012 European Society of Cardiology heart failure guidelines.⁴²

Specific needs of people with heart failure

Symptoms, functional limitations, and quality of life

The most common symptoms of heart failure are pain, breathlessness, fatigue, and depression. Most patients describe at least one symptom as burdensome.⁴³ Patient reported health status—which typically integrates symptom burden and captures the domains of symptoms, functional status, and health related quality of life—is an important measure of cardiovascular health.⁴⁴ Notably, in a US study of 84 patients with heart failure, physical symptom burden was the strongest predictor of health related quality of life.⁴⁵ A UK study that assessed health status in 179 patients with heart failure over a three year

period found that quality of life scores were lower in patients with a higher New York Heart Association functional class, a poor socioeconomic status, and those who lacked social support.⁴⁶

When heart failure nears end stage, it has one of the largest effects on quality of life of any advanced disease.⁴⁷ In a US study of 60 patients with symptomatic heart failure and 30 with advanced lung or pancreatic cancer, those with advanced heart failure reported greater symptom burden and depression as well as lower spiritual wellbeing than those with advanced cancer.³⁴ Palliative care focuses on patients' quality of life and symptom burden, which are central challenges in patients with heart failure.

Multimorbidity

Heart failure is associated with substantial morbidity and with multiple other comorbidities. Multimorbidity contributes to the range of symptoms, complicates management, and can alter prognosis. On average, patients with heart failure have 4.5 comorbidities.⁴⁸ In a 1998-2008 analysis of 1395 patients with self reported heart failure, the proportion of patients who had five or more comorbid conditions increased from 42% to 58% over that period (P<0.01).⁴⁹ The presence of additional comorbidities also leads to polypharmacy, which increases patient and family burden. In the same cohort, the number of prescription drugs increased from 4.1 in 1998 to 6.4 in 2008 (P<0.01).⁴⁹

Frailty

Patients with heart failure are also affected by frailty. Frailty is a biologic syndrome characterized by a decline in overall function and loss of resistance to stressors.⁵⁰ Several studies have shown that frailty is more prevalent in people with heart failure than in the general elderly population.^{51,52} Frailty measures contribute to risk estimates for adverse outcomes.⁵³ The care needs of patients

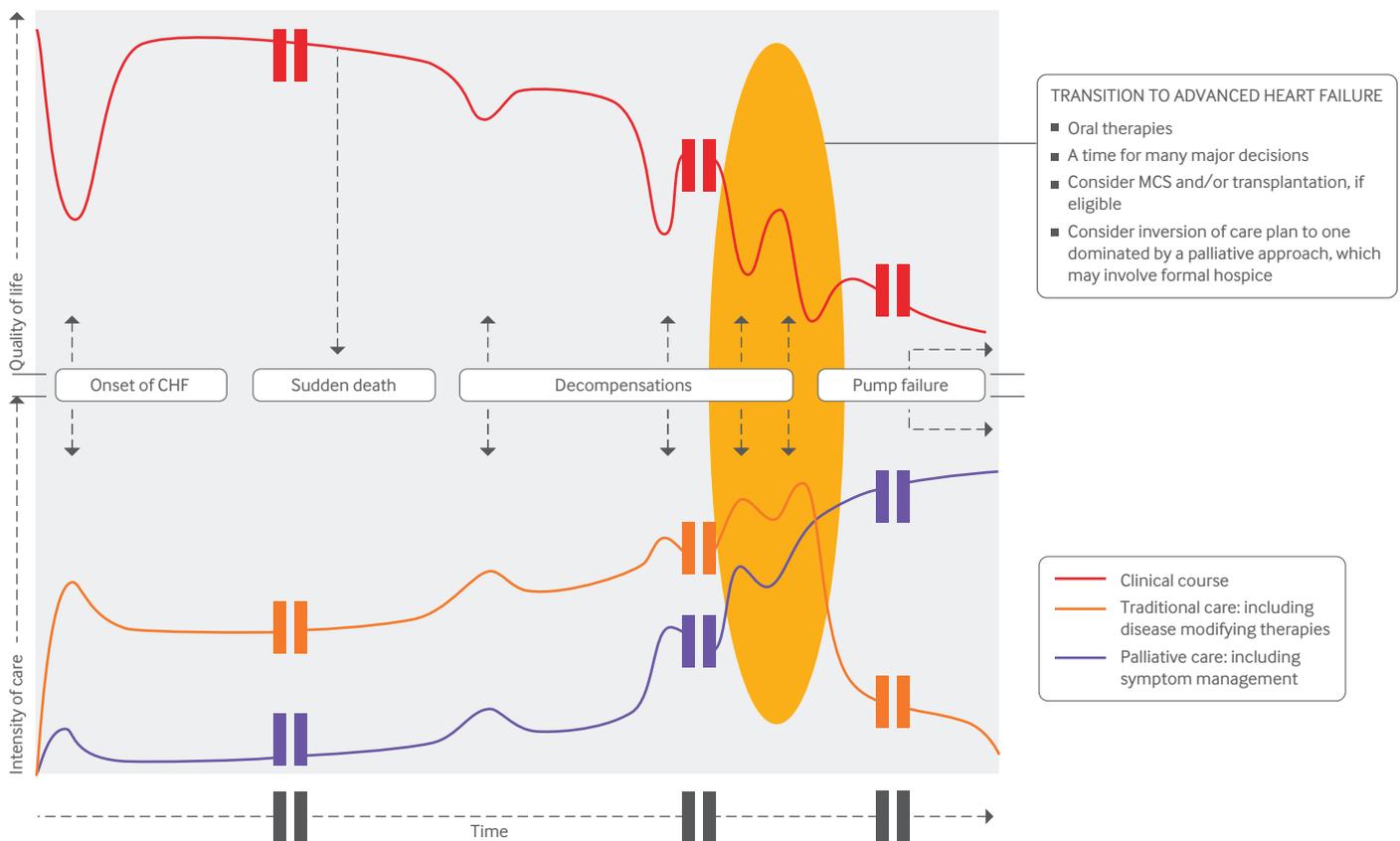


Fig 2 | Clinical course of heart failure with associated types and intensities of available therapies and incorporation of palliative care. Red line (clinical course): patients tend to follow a progressive, albeit non-linear, decline in health related quality of life; this course can be interrupted by sudden cardiac death caused by arrhythmia or can end in a more gradual death from progressive pump failure. Yellow line (traditional care): at disease onset, multiple oral drugs are prescribed for cardiac dysfunction or comorbidities (or both). As disease severity increases, the intensity of care may also increase, with intensification of diuretics, addition of an implantable cardioverter defibrillator or cardiac resynchronization therapy for those eligible, and increasing interaction with the medical system through ambulatory visits and hospital admissions, until standard therapies begin to fail (transition to advanced heart failure). Purple line (palliative care): palliative therapies to control symptoms, improve quality of life, and enhance communication are relevant throughout the course of heart failure, not just in advanced disease, working together with traditional therapies designed to prolong survival. The critical transition into advanced heart failure from the medical perspective is often followed by a transition in goals of care from the patient and family perspective, when palliative therapies may become the dominant treatment paradigm (for the majority of patients, in whom transplantation and mechanical circulatory support are not an option). Clinicians must recognize the transition to advanced heart failure so that therapeutic options can be considered in a timely fashion and patients can proactively match medical decisions to clinical realities. CHF=chronic heart failure; MCS=mechanical circulatory support *Adapted, with permission, from the American Thoracic Society^{39,40}

with heart failure and frailty are often not very amenable to traditional heart failure treatments; palliative care can help with manifestations of frailty by providing a patient centered framework to care grounded in overall values, goals, and preferences.

Palliative care interventions

The basic principles, general evidence based management strategies, and expected benefits of palliative care clearly apply to the highly symptomatic and functionally limited heart failure population. Furthermore, heart failure rarely occurs in isolation, so that integrated approaches to care, which consider advanced age, multimorbidity, and frailty are applicable to most patients with heart failure. A palliative care specialist is not needed to prescribe many of the interventions; most primary care or cardiology clinicians, particularly with some training, can provide these services.

There are several pharmacologic and non-pharmacologic management strategies for common heart failure symptoms. Opioids are the first line therapy for moderate

to severe pain, unless the pain is caused by another condition (for example, angina).⁵⁴ Non-pharmacologic management includes massage, acupuncture, and heat therapy.

Dyspnea refractory to hemodynamic interventions (diuretics, afterload reduction, inotropes) can also be treated with low dose opioids and benzodiazepines. Non-pharmacologic management includes using a fan to provide cool air to the face, breathing training, and anxiety management.

The first step is to identify depression and treat its causes, including pain and dyspnea.⁵⁵ Selective serotonin reuptake inhibitors are most often used as first line pharmacologic therapy owing to their general effectiveness and limited side effects. Non-pharmacologic management includes exercise, psychotherapy, and cognitive behavioral therapy.

There are few data supporting specific interventions for patients with heart failure. Trials on the use of opioids for treating dyspnea in heart failure have been small and the results have been conflicting in terms of effectiveness,

although opioids did seem to be safe.^{56,57} The Sertraline Against Depression and Heart Disease in Chronic Heart Failure (SADHART-CHF) trial of 469 patients found no significant difference in depression or cardiovascular status in the treatment group compared with placebo, and sertraline was well tolerated.⁵⁸ In the Depression and Self-Care of Heart Failure trial of 158 patients with heart failure, cognitive behavioral therapy plus usual care was compared with usual care alone. The primary outcome was the Beck depression inventory score at six months, and the self care of heart failure index confidence and maintenance subscale scores were co-primary outcomes. Cognitive behavioral therapy was administered by two masters level and two doctoral level therapists. Cognitive behavioral therapy was effective in the treatment of depression in patients with heart failure compared with usual care (Beck depression inventory score 12.8 (standard deviation 10.6) v 17.3 (10.7); $P=0.008$), but it did not influence self care.⁵⁹ Further evidence on appropriate and effective pharmacologic and non-pharmacologic interventions for the treatment of heart failure symptoms is needed.

Integrating palliative care into heart failure care

Palliative care is currently poorly integrated into the care of heart failure. A survey study from the UK with 499 respondents (42% palliative care providers) reported that 47% of palliative care providers received less than 10 referrals and only 3% received more than 50 referrals of patients with heart failure annually.⁶⁰ Incorporation of palliative care is complicated by the uncertainty of the heart failure disease process and the complexities of communication around this uncertainty. The presence of frailty and multimorbidity in many patients with heart failure, and silos of care, further complicate the union between these two disciplines. These factors are discussed below.

Uncertainty in the heart failure disease trajectory

Heart failure often follows an unpredictable course, with periods of stability interrupted by exacerbations, sometimes ending in sudden death or competing non-cardiovascular illness, but most typically culminating in irreversible pump failure. Acute exacerbation often represents a temporary reduction in health status but can be a terminal event; at the time of presentation it can be nearly impossible to anticipate the patient's response to therapy and eventual disposition. Not surprisingly, many patients experience uncertainty and confusion regarding the characteristics, treatments, and expected outcomes of their illness.

To complicate matters many patients with heart failure overestimate their survival. In a study comparing patient predicted life expectancy and model predicted life expectancy, patients overestimated their life expectancy by 40%.⁶¹ Superficially this makes it difficult to identify the optimal timing to involve palliative care,^{62,63} although palliative care can be especially helpful when the disease trajectory and prognosis are difficult to quantify. Palliative care focuses on quality of life for the individual, regardless of prognosis. Ultimately, the ideal timing of the involvement of palliative care varies with the patient.

Poor communication

Effective communication between healthcare providers and patients is essential, especially in chronic diseases, such as heart failure. End of life discussions are often time consuming and require navigating the complex needs of patients and families. Nonetheless, such discussions improve quality of life for both patients and caregivers. Most patients and families desire open, honest, and accurate information on the disease involved.⁶⁴⁻⁶⁶ Unfortunately, cardiology providers have reported an unwillingness to discuss information such as poor prognosis. In a qualitative cross sectional study that included 12 palliative care and cardiology providers, all identified prognostication as a barrier to effective communication.⁶⁷

Avoidance of difficult discussions about end of life is probably exacerbated by a lack of training in palliative and communication techniques. In a multi-site survey of 95 cardiology and primary care physicians, nurse practitioners, and physician assistants, almost a third reported a low or very low level of confidence in initiating prognosis or end of life discussions, enrolling patients in hospice, or providing end of life care.⁶⁸ Even more striking, only 12% reported having annual end of life discussions with their patients.⁶⁴ Some cardiology providers think that increased education and training is needed in relation to communication, while others think that it is the role of the palliative care team to initiate these conversations.⁶³ Increased education and training must be part of the solution, because integration of palliative care earlier in the disease process requires delivery from a range of providers; the formal palliative care workforce is not large enough to assume all of these responsibilities.

The first step to effective communication is to elicit the patient's beliefs, values, and goals. A qualitative study of 20 patients with advanced heart failure from Canada aimed to understand patient preferences of prognosis communication. Patients expressed a desire to discuss their prognosis earlier in the disease process and preferred a physician to initiate these discussions.⁶⁶ Because heart failure is a chronic process with an unpredictable trajectory, early and iterative solicitation of values, goals, and preferences is necessary to guide the range of treatment options and decisions.³⁹ It is important to revisit these areas. A secondary analysis of the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) analyzed the resuscitation preferences of 114 patients with heart failure. Twenty three per cent of patients admitted to hospital with heart failure preferred not to be resuscitated. Overall, 19% of patients changed their resuscitation preferences over a two month period.⁶⁹ Clarification of beliefs and preferences should result in the right interventions being given to the right patients.

Silos of care

Multidisciplinary care in heart failure has been shown to improve survival,^{70,71} but integrating care across disciplines can be logistically challenging for providers and patients. An increasingly specialized medical system in which inpatient and outpatient services are separated, often with non-communicating electronic health records,

has created a fractionated system that works against the integrated holistic approach to management that is at the center of palliative care. A UK survey study found that only a little over half of palliative care physicians and nurses reported some form of collaboration with cardiology.⁶⁰ Unclear roles in the partnership between cardiology and palliative care contribute to the silos of care. Not surprisingly, both patients and family members report confusion over which providers are directly involved in a patient's care.

Lack of knowledge

The reasons for ineffective collaboration stem partly from lack of knowledge about palliative care and hospice. A qualitative survey study of 18 cardiology and primary care providers found that many did not know the differences between palliative care and hospice, including the eligibility criteria for these services.⁶³ The fact that many providers have false perceptions about palliative care (for example, that it is appropriate only at the end of life or that patients will lose all hope if it is discussed) means that patients are much less likely to be referred to palliative care. Furthermore, patients remain uninformed, with over 90% of adults in the US reporting that they have either no knowledge or limited knowledge of palliative care.⁷² To help bridge this gap, there is a need for general acceptance of palliative care by providers and patients, as well as education around the roles and functions of such care.

Complex treatment decisions

Patients face various treatment decisions during the course of heart failure, all of which have associated risks and benefits. Interventions, such as percutaneous or surgical valve repairs or replacements and coronary artery bypass grafting, have the potential to improve cardiac function, but they carry risks. In addition, several adjunctive therapies such as intravenous inotropes, renal replacement therapy, and temporary mechanical support have the potential to treat acute decompensated heart failure, but they carry the potential of chronic dependence.³⁹

Implantable devices, such as implanted cardioverter defibrillators (ICDs) and left ventricular assist devices (LVADs), are increasingly becoming a treatment option. Decision making and patient selection are important components of palliative care, and strategies that provide patients with all medically appropriate options—including a full range of outcomes—are necessary to help patients navigate these complex decisions.

Implanted cardioverter defibrillators

Decisions on ICD implantation must be grounded in patients' beliefs and wishes around end of life care. ICDs can prevent death from a lethal arrhythmia but do not improve cardiac function (unless cardiac resynchronization therapy with biventricular pacing is also indicated) and can add to the burden, particularly if the ICD discharges inappropriately. An ICD may also increase the likelihood of a prolonged death from pump failure or the risk of hospital admission.⁷³

The variable use of and perceptions of patients considering ICD therapy highlights the need for improved care

and communication around this process.⁷⁴ Partly because of palliative care's holistic approach to care and its focus on relief of suffering, it can play an important role in clarifying expectations and patient beliefs around this therapy. There is growing interest in appropriate patient selection and decision making for ICDs. Guided by palliative care principles, guidelines and quality measures are beginning to focus on providing a high quality shared decision making discussion, rather than the implantation process itself. For example, the 2013 ACC/AHA guidelines include a class I recommendation for implantation of an ICD for primary prevention of sudden cardiac death in selected patients with heart failure. A footnote to this recommendation states that a discussion should occur with each patient about the risks, benefits, and alternatives of ICD therapy and this discussion should be documented.¹

Left ventricular assist devices

LVADs are increasingly implanted in carefully selected patients with advanced heart failure who cannot undergo transplantation or for whom a suitable donor organ is not available. Deciding whether to proceed with LVAD implantation involves a complex assessment of the severity of heart failure, comorbidities, frailty, caregiver burden, and lifestyle changes.^{75 76}

Currently, the International Society of Heart and Lung Transplantation guidelines for mechanical circulatory support include a class IIa recommendation to consult palliative care during the LVAD evaluation period. The society specifies that goals and preferences for end of life should be discussed as part of this consultation.⁷⁷

In 2013, the Joint Commission—a certifying body in the US—mandated that all accredited destination therapy (DT) LVAD programs must have a palliative care specialist as part of the team.⁷⁸ In parallel, an update to the national coverage determination for bridge-to-transplant and DT-LVADs from the Centers for Medicare and Medicaid Services required the multidisciplinary team to include a palliative care provider.⁷⁹ Patients with LVADs are at risk of stroke, bleeding, infection, and other complications that contribute to an average survival after implantation of less than five years.⁸⁰

Device deactivation

Decisions around deactivation of these devices can be even more complex than the decision to implant them.⁸¹ Studies show that most patients with ICDs do not understand how they work or that there is an option to deactivate them.⁸² Furthermore, providers rarely discuss ICD deactivation.^{83 84} The result is that ICDs remain active until, and often during, death; disturbingly, this even happens to patients in hospice.^{85 86} Consultation with palliative care can help clarify the goals of care.⁸⁷ Deactivating an ICD does not result in almost immediate death as it does with an LVAD. Discussions around end of life and deactivation in people with LVADs are especially complicated.⁸⁸ With DT-LVADs, death will occur with the LVAD in place. The opinions and comfort levels of providers around LVAD deactivation are varied, with some providers viewing it as an act of euthanasia.⁸⁹ Patients' beliefs—including spiritual and cultural—are important

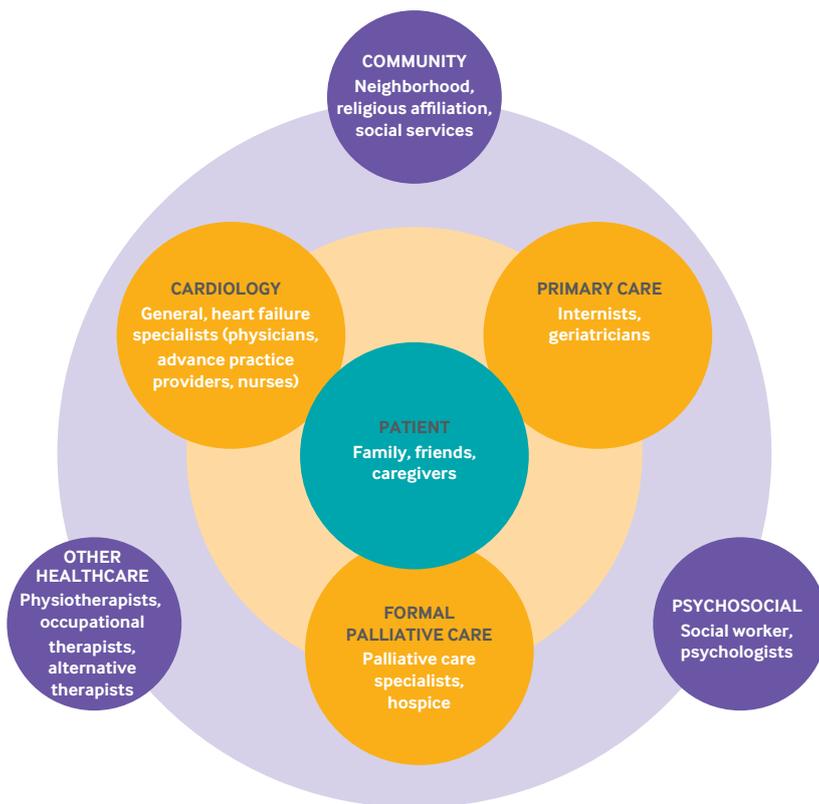


Fig 3 | Team based palliative care. Adapted from Fendler TJ and colleagues⁹²

factors in these decisions. Iterative discussions around device deactivation, starting before implantation, are essential to decrease confusion for providers, patients, and their families. Data are lacking on the best way to involve palliative care in the treatment of these patients, but palliative care specialists often play a key role at the time of deactivation.^{90,91}

Evolving approaches

Primary palliative care and team based care

Despite these challenges, a team based approach is essential to the care of patients with heart failure and is potentially facilitated by the integration of palliative care (fig 3). Access to formally trained palliative care providers may be limited; therefore, other members of the patient's care team, including primary care providers and cardiologists, should be familiar with available palliative resources and treatment options.¹ A collaborative relationship between primary care, cardiology, and palliative care can lead to improved communication and understanding of patients' goals and better end of life experiences.⁹³

In the early phase of the disease, a general practitioner or cardiology provider can lead the team with formal palliative care consultation only as needed. Non-palliative care specialists should be empowered by palliative care providers and through skills training to practice primary palliative care with all patients. In end stage heart failure or at the time of major medical decisions (such as consideration of LVAD implantation), trained palliative care providers may take on a more central role in coordinating care. To decrease patients' confusion and prevent feelings

of abandonment, improved communication around these transitions is essential. In a UK survey study with 499 respondents, more than 80% of palliative care providers (42% of total sample) thought that end of life care was not discussed with patients by their cardiology providers before being referred for palliative care.⁶⁰ One solution in advanced disease may be to appoint a member of the cardiology team to provide the link with palliative care. Several studies have reported effective collaborations involving a heart failure nurse or case manager who liaises between the two teams.⁹⁴⁻⁹⁶

There is a shortage of providers trained in palliative care for the population in need.⁹⁷ Specialty certification from the American Academy of Hospice and Palliative Medicine requires a 12 month fellowship in an accredited hospice and palliative medicine program and boards testing.⁹⁸ Specialty certifications are also available for nurses, social workers, and chaplains. Masters degree programs have also been developed for physicians, nurse practitioners, physician assistants, and nurses who are interested in becoming community palliative care specialists. But given the large need, provision of primary palliative care services by non-palliative care providers will always be an essential part of heart failure care. Educational programs, for example, workshops, seminars, and integrated tracks at specialty conferences (such as cardiology)—are needed for providers who do not feel comfortable with palliative care principles. Creating incentives for skills training in palliative care principles, such as offering continuing medical education credits, regardless of specialty, can also help bridge the gap. In order to educate future providers, it will be important to introduce palliative care principles during the educational process. The Accreditation Council for Graduate Medical Education focuses on six core competencies, which include interpersonal and communication skills. To ensure a competent and skilled workforce, it will be crucial to incorporate concepts such as shared decision making, as well as education about primary palliative care.

Advance care directives and preparedness planning

For patients, advance care directives provide an avenue to express their wishes about life sustaining treatments, usually to withhold or withdraw, in the event of a terminal condition.⁹⁹ For providers, advance care directives can help when assessing patients' values, goals, and preferences to facilitate concordant treatment decisions. Although the role of advance care directives is obvious in patients with chronic illness, they are not used to their full capacity in patients with heart failure. In a longitudinal study of 608 US patients with heart failure, more than half of patients did not have an advance directive at the time of death.¹⁰⁰ There are plenty of opportunities for improving the completion and documentation of advance care directives in patients with heart failure.

Ideally, advance care planning should start early in the disease process and progress iteratively through the course of the disease. Moving advance care planning upstream involves preparedness planning. Advance care directives have traditionally focused on end of life care, while preparedness planning focuses on preparing for any adverse event. Preparedness planning has been

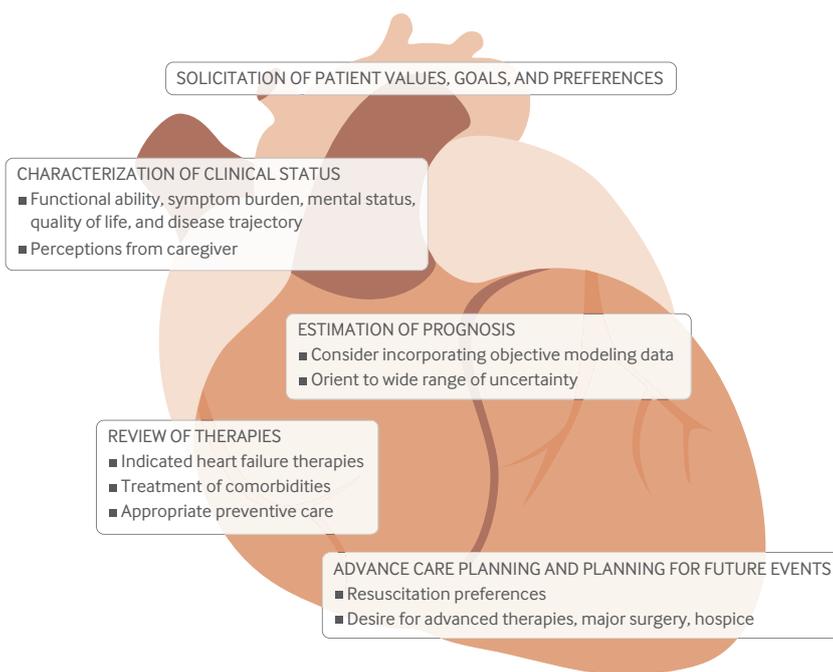


Fig 4 | Components of an annual heart failure review. Adapted, with permission, from Allen and colleagues³⁹

shown to improve attitudes and increase completion of advance care directives in patients with heart failure.¹⁰¹ The concept of preparedness planning is often combined with a palliative care visit as the first step to the ultimate completion of advance care directives. The focus of preparedness planning is specific to the individual patient's situation, and it focuses on respecting patients' beliefs and preferences.¹⁰²

It is not clear who should deal with these matters. Ideally, the patient's primary care provider or cardiology should initiate these discussions. Moving initial discussions to the period soon after diagnosis may help alleviate some of that confusion by placing responsibility on the diagnosing provider. To ensure these discussions happen over time, the AHA has proposed an "annual heart failure review" to encourage iterative discussions about goals of care and as a way to improve advance care planning (fig 4).³⁹

Payment for advanced care planning

In support of these recommendations, the US Centers for Medicare and Medicaid Services issued a proposed rule that updates the Medicare Physician Fee Schedule on or after 1 January 2016 to establish separate payment for two advanced care planning services provided to Medicare beneficiaries by physicians and other practitioners.¹⁰³ The Medicare statute currently provides coverage for advance care planning under the "welcome to Medicare" visit available to all Medicare beneficiaries, but they may not need these services when they first enroll. Establishing separate payment for advance care planning codes enables beneficiaries and practitioners to utilize these paid-for planning sessions at the most appropriate time, such as after a diagnosis of heart failure or progression of heart failure into later stages of the disease.

Although this policy change covers a relatively small aspect of a patient's overall care, it represents a major change in the acceptance of palliative care and advanced care planning services as a component of routine care; less than a decade ago a similar plan failed after being decryd as tantamount to setting up "death panels" that could cut off care for sick people. Progressive integration of preparedness planning into routine practice, in both internal medicine and cardiology settings, combined with a broader cultural acceptance of end of life planning would provide an important foundation for broader efforts to expand palliative care to patients with heart failure.

Shared decision making and decision support

Patient centered care is central to the concept of palliative care. The idea of restructuring the health delivery system around the patient is gaining traction with professional and policy organizations.¹⁰⁴⁻¹⁰⁵ Patient satisfaction scores, transitional care measures integrating inpatient and outpatient settings, and patient reported outcomes are two patient centered initiatives that are particularly applicable to heart failure.

Shared decision making

Shared decision making puts patient centered care into practice. It involves both patients and providers, with the ultimate goal of ensuring that a patient's values, goals, and preferences guide informed decisions. Shared decision making recognizes that there are often complex trade-offs when taking medical decisions and it fulfills the ethical and legal mandate to fully inform patients of all risks and benefits of a treatment.¹⁰⁶⁻¹⁰⁸ This is particularly true in heart failure, where several medical decisions (such as whether to insert a LVAD) are preference sensitive owing to their high risk-high reward nature. The tenets of palliative care are fundamentally patient centric, and the specialty places shared decision making and related patient-provider communication at the forefront of management.

Decision aids

These are tools designed to facilitate shared decision making and patient participation in healthcare decisions.¹⁰⁹ They are not substitutes for conversations with healthcare providers but tools to help frame the discussions and inform patients of their options. Various forms of decision aids are available, including pamphlets, videos, interactive web based platforms, and books.¹¹⁰ A recent systematic review of tools used to promote shared decision making in critically ill patients showed that the use of decision aids improved knowledge and awareness of treatment choices.¹¹¹ Decision aids are increasingly available but have not been widely adopted because of the difficulty of integrating them into clinical practice. Decision aids have been developed for some heart failure treatments, including ICDs and LVADs (<https://patientdecisionaid.org/>).¹¹² However, decision aids are needed for other high stakes decisions such as transplantation, home inotropic therapy, and hospice. Future work should focus on the implementation of decision aids to increase their use in clinical practice,¹¹³ and the principles of palliative care can help guide this process.

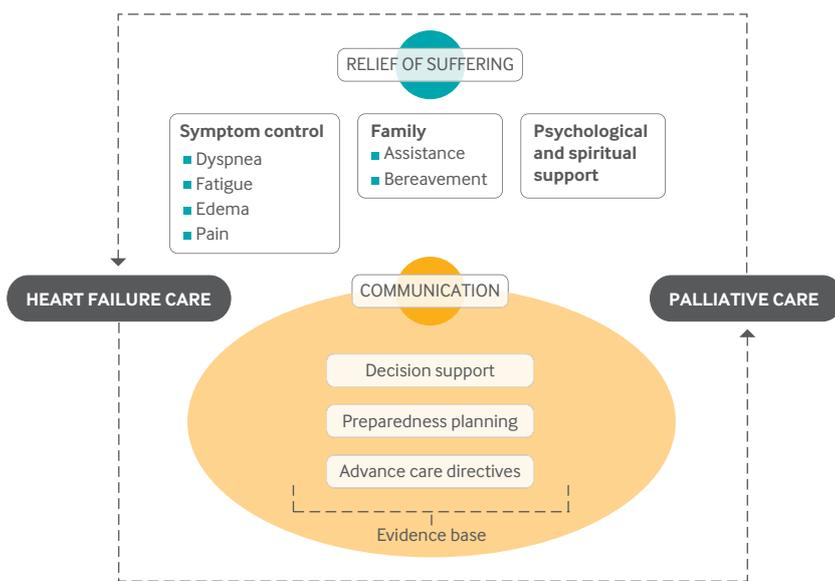


Fig 5 | Integration of palliative care and heart failure

Expanding the evidence base

To ensure that palliative care is integrated into the management of heart failure, there is a need for high quality evidence to support its role.¹¹⁴ Little evidence is available on the direct outcomes of palliative care in patients with heart failure, including how best to incorporate this specialty. Systematic and consistent evidence is lacking worldwide. This evidence is crucial because of the important cultural and environmental differences in the way palliative care services are provided. Physician (or Medical) Orders for Life-Sustaining Treatment (POLST/MOLST) programs, the Institute for Healthcare Improvement conversation project, the efforts of the Coalition to Transform Advanced Care, and the “five wishes” advance directive of the Aging with Dignity organization are widely used despite the absence of compelling evidence that they improve patient outcomes.¹¹⁵

Fortunately, some data are emerging. The Palliative Care in Heart Failure (PAL-HF; NCT01589601) trial is a prospective, controlled, unblinded, single center study of an interdisciplinary palliative care intervention in 200 patients with advanced heart failure estimated to have a high likelihood of mortality or readmission. The six month PAL-HF intervention focuses on physical and psychosocial symptom relief, attention to spiritual concerns, and advanced care planning.¹¹⁶ Secondary outcomes include impact on anxiety, depression, spiritual wellbeing, caregiver satisfaction, and cost and resource utilization. The results of this trial, expected after July 2016, will help provide further data on the usefulness of palliative care interventions in patients with heart failure.

Similarly, the Collaborative Care to Alleviate Symptoms and Adjust to Illness in Chronic Heart Failure (CASA; NCT01739686) trial is expected to be completed by December 2016 and will provide randomized data on whether an intervention to improve symptoms and quality of life by integrating palliative and psychosocial care into chronic care is feasible and improves patient outcomes.^{117 118}

A study in Germany is aiming to identify the barriers and facilitators of palliative care in patients with chronic heart failure. Using a quantitative and qualitative approach, it will solicit opinions on why the use of palliative care remains low in Germany and apply this information to develop processes that can overcome these barriers.¹¹⁹ With such efforts, evidence on how and when to incorporate palliative care into the management of heart failure should improve the overall care for these patients (fig 5).

Future directions

The landscape in heart failure is shifting, with increased attention on palliative and end of life care. Several objectives need to be met before we can move towards a more comprehensive approach to the management of this disease.

Firstly, more frequent, timely, quasi-experimental trials are needed that assess patient centered outcome measures for symptom based and end of life care. Researchers focused on intervention design will need to do a better job of understanding the cultural milieu and individual behaviors that dictate care decisions in patients with symptomatic heart failure.

Secondly, professional and policy organizations must continue to emphasize and incentivize palliative care, including discussions around end of life. Although the Affordable Care Act does not explicitly mention palliative care, it does cover some aspects of end of life care, including hospice. Other policy organizations are also working to influence end of life care.

The Coalition to Transform Advanced Care has worked to influence federal and state policies. Priority initiatives include the advanced care project to identify, analyze, and implement best clinical care models to improve care for patients and families living with advanced illness; and the community action project, which aims to bring together health systems and community based organization to improve advanced illness care.¹²⁰ Although the Centers for Medicare and Medicaid Services plan to reimburse physicians for engaging patients in advance care planning discussions,¹⁰³ it is unclear whether this will improve end of life care.¹²¹

Furthermore, the Joint Commission has introduced performance measures for advanced heart failure certification that include discussions of advance care planning and advance directive documentation; however, most hospitals have chosen not to participate in such certification and enrollment has stagnated.

Thirdly, patients, family members, and healthcare providers must be better informed about palliative care. The perception of palliative care needs to expand from purely end of life care to care that focuses on symptom burden and stress as a way to improve quality of life throughout disease progression. Better integration of palliative care into the management of heart failure requires increased training for providers on end of life care and solicitation of patients’ values, goals, and preferences. Several training models have been developed to help providers communicate disease trajectory and prognosis. However, better ways of effectively communicating with patients need to be explored.

Fig 6 | Inclusion of palliative care in heart failure guidelines

Professional organization	Class (strength) of recommendation	Level of evidence	Guideline
2013 ACC/AHA Guidelines for the Management of Heart Failure	Class 1	B	Consider palliative care or hospice care throughout the hospital stay, before discharge, at the first visit after discharge, and during follow-up visits in selected patients
	Class 1	B	Palliative and supportive care are effective for patients with symptomatic advanced heart failure to improve quality of life
2013 ISHLT Guidelines for Mechanical Circulatory Support	Class IIa	C	Palliative care consultation should be a component of the treatment of end stage heart failure during the evaluation phase for mechanical circulatory support. In addition to symptom management, goals and preferences for end of life should be discussed with patients receiving mechanical circulatory support as destination therapy
	Class 1	C	Consultation with palliative medicine should be considered before mechanical circulatory support implantation to facilitate discussion of end of life issues and establish an advance directive or living will, particularly when implanted as destination therapy
2012 ESC Guidelines for the Diagnosis and Treatment of Acute and Chronic Heart Failure	Class 1	A	It is recommended that patients with heart failure are enrolled in a multidisciplinary care management program to reduce the risk of hospital admission for heart failure
2010 HFSA Comprehensive Heart Failure Practice Guideline		C	It is recommended that patient and family or caregiver discussions about quality of life and prognosis be included in the disease management of heart failure
		C	It is recommended that end of life care strategies be individualized and include core heart failure pharmacologic therapies, effective symptom management, and comfort measures, while avoiding unnecessary testing. New life prolonging interventions should be discussed with patients and caregivers, with careful discussion of whether they are likely to improve symptoms
		C	It is recommended that a specific discussion about resuscitation be held in the context of planning for overall care and for emergencies with all patients with heart failure. The possibility of sudden cardiac death for patients with heart failure should be acknowledged. Specific plans to reduce sudden cardiac death (for example, with an ICD) or to allow natural death should be based on the individual patient's risks and preferences for an attempt at resuscitation, with specific discussion of risks and benefits of inactivating the ICD. Preferences for attempts at resuscitation and plans for approach to care should be readdressed at turning points in the patient's course or if potentially life prolonging interventions are considered

ACC=American College of Cardiology; AHA=American Heart Association; ISHLT=International Society of Heart and Lung Transplantation; ESC=European Society of Cardiology; HFSA=Heart Failure Society of America; ICD=implanted cardioverter defibrillator

Lastly, cultural acceptance of end of life planning is the key to continued progress. If death is consistently viewed as failure rather than an important chapter of life, patients and families are bound to be ill prepared when heart failure becomes unresponsive to therapies. One example of how end of life culture can evolve is found in La Crosse, Wisconsin. In 1991, the Gundersen Health System implemented the Respecting Choices program for advanced care planning and decision making. The program has three components:

- Patient educational materials are routinely available at local health facilities
- Trained advance care planning facilitators help people with advance care planning when requested
- Practices within the healthcare organizations enable providers to easily obtain, store, and retrieve advance directives when and where they are needed.¹²²

In a review of 540 La Crosse deaths in the mid-1990s, written advanced directives were found in 85% of the sample, and the treatment preferences expressed in those documents seemed to be known by the families and physicians.¹²³ A subsequent study using the same advance care planning model of those initial 540 adults who died in 1995-96 examined 400 additional adults who died in 2007-08 and reported a decrease in treatments at the end of life and a statistically significant increase in the prevalence of written advance directives (90% v 85%; P=0.02).¹²⁴ Whether such efforts can be widely disseminated and maintained remains unclear, but the La Crosse example provides some hope.

Conclusion

Heart failure remains a highly morbid and lethal diagnosis. Advances in care have delayed the progression of disease but rarely lead to cure, such that the demands of heart failure on patients, caregivers, and healthcare

systems are as great as ever. Palliative care is designed to complement traditional heart failure care through its focus on communication, shared decision making, and advance care planning. Palliative care strives primarily to reduce suffering through the relief of pain and other distressing symptoms while integrating psychological and spiritual aspects of care. Importantly, palliative care also provides a support system to help families cope during illness and bereavement. Palliative care is useful early in the course of illness, often in conjunction with other therapies that are intended to prolong life; it intends neither

CAREGIVERS' PERSPECTIVES

We solicited feedback from three caregivers of patients who died of end stage heart failure. Their experiences differed greatly. One was the wife of a patient who chose palliative care and ultimately hospice with death occurring in the home. The other two were a sister and daughter of a patient who received a left ventricular assist device (LVAD) and died after multiple complications in a long term acute care facility. All three caregivers thought that introducing palliative care earlier in the process of the disease would have been beneficial: "In my opinion the sooner you get the patient and caregiver in touch with palliative care, the easier it is for them to make decisions." Additionally, they all thought that palliative care would be useful when making treatment decisions: "I think this is such an important topic, and one that is too often not discussed with patients and their families when discussing treatment options." Furthermore, the daughter of the patient who received an LVAD was emphatic about increasing the role of palliative care in patients with end stage heart failure: "As an educated and close knit family, this experience [of pursuing an LVAD] literally brought us to our knees as we tried to navigate the complexity of the decision making process. We would have benefitted tremendously from a palliative care approach." On the basis of this feedback, we highlighted the need for more robust evidence and integration of palliative care interventions for patients with heart failure.

QUESTIONS FOR FUTURE RESEARCH

- How can palliative care techniques be best taught to a wide range of clinicians for earlier integration into routine care?
- For patients with heart failure, what is the best method for integrating secondary and tertiary palliative care?
- What components of existing palliative care interventions provide the greatest increase in health related quality of life to patients with heart failure?

to hasten nor postpone death. For all of these reasons, palliative care has clear applications to heart failure, particularly in advanced disease but also in earlier stages. Greater integration of palliative care in the management of heart failure has the potential to handle clinical uncertainty, create integrated care that is patient centered and spans various comorbidities and silos of care, improve communication, and ease the introduction of life saving devices with complex trade-offs. To realize these opportunities, considerable effort is needed to improve the evidence base for palliative care interventions, develop better decision aids and communication training, and ultimately change the culture around end of life.

Guidelines

Please see fig 6.

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