

## End-of-Life Care in the Treatment of Heart Failure in the Elderly

John Arthur McClung, MD<sup>a,b,\*</sup>

<sup>a</sup>*Division of Cardiology, Westchester Medical Center/New York Medical College,  
Valhalla, NY 10595, USA*

<sup>b</sup>*Bioethics Institute, New York Medical College, Valhalla, NY 10595, USA*

The American Geriatrics Society position statement on the care of dying patients opens by stating that, “providing excellent, humane care to patients near the end of life, when curative means are either no longer possible or no longer desired by the patient, is an essential part of medicine” [1]. Although the essential nature of this discipline certainly cannot be denied, much of the literature dedicated to this topic has revolved around terminal care provided to patients who have neoplastic diagnoses. Heart failure (HF) presents its own unique challenges to the clinician who desires to make the recommendations of the American Geriatrics Society a tangible reality. This article focuses on both specific clinical recommendations and an analysis of some of the ethical issues involved in the provision of care to elderly patients in the terminal stages of HF.

### How do we know we have arrived?

The ability of physicians to predict mortality accurately has been demonstrated recently to be questionable, even in cases of advanced malignancy [2,3]. Attempts to ascertain variables predictive of mortality in patients who have HF have proven to be significantly more difficult. An exhaustive review of the literature conducted during the last decade found very few consistently predictive variables. Factors accounting for this included small sample size, differing patient populations, selective acquisition of variables, interrelationship of variables, differing measurement technologies, duration of follow-up, poor reproducibility, and problems with data handling [4].

---

This work was supported in part by a grant from the Dr. I Fund Foundation.

\* Division of Cardiology, Westchester Medical Center, Valhalla, New York 10595.

E-mail address: john.mcclung@jhu.edu

Measures that appear to have consistent independent prognostic value include New York Heart Association symptom class, echocardiographic left ventricular dimensions, radionuclide ejection fraction, and ischemic cause. Hyponatremia previously has been documented to be associated with an extremely negative prognosis; however, it is unclear whether or not this remains as robust an indicator in patients treated with angiotensin-converting enzyme (ACE) inhibitors [4,5].

Patients who have HF present with the additional challenge of sudden death, which makes the generation of prediction models even more difficult. As many as 60% of patients who have HF die suddenly; however, prediction of who is most likely to suffer sudden death remains controversial [6,7]. Recent attempts to determine who is expected to die suddenly include studies of the prognostic efficacy of B-type natriuretic peptide (BNP) and a risk factor assessment that includes ejection fraction, LV end-diastolic diameter, BNP level, presence of nonsustained ventricular tachycardia, and diabetes mellitus [8,9]. Accurate assessment of sudden death incidence is rendered all the more difficult by the increased prevalence of automatic internal cardioverter-defibrillator insertion in patients who have reduced ejection fraction, which concurrently enhances data collection about the incidence of dysrhythmia in patients who have HF and decreases the overall mortality attributable to dysrhythmia [10,11].

The estimation of overall prognosis in cardiac failure has been equally elusive. A recent study of patients in Europe with a mean age of 69.7 years previously diagnosed with HF generated a clinical model that scored age, sex, history of diabetes, history of renal insufficiency, ankle edema, weight, low blood pressure, and the absence of beta-blocker therapy by a regression coefficient. Using this model, patients who scored very high had a mortality as high as 78% over the 18-month observation period [12]. Patients who had lower scores had significantly greater variability in mortality. This observation also needs to be placed in the context of the increasingly frequent use of resynchronization therapy, which, in combination with an internal cardioverter-defibrillator, has been demonstrated to reduce overall mortality by 36% [13].

The persistence of this prognostic uncertainty renders a discussion of patient preference difficult at best. Prior work done in patients who have cancer diagnoses suggests that even a 10% probability of not surviving the next 6 months leads patients to consider different treatment options [14]. In part because of prognostic uncertainty, patients dying of HF have been documented to have both a poorer understanding of their condition and less involvement in the decision-making process regarding their care [15]. A study of 274 dying patients, 26% of whom had cardiovascular disease, found that some treatment was withheld or withdrawn in 84% of patients; however, only 35% of these patients were able to participate in the decision-making process [16].

Patients dying of HF who do not die suddenly, deteriorate gradually; however, this gradual process is interrupted by acute episodes that frequently

require hospitalization (Fig. 1) [15,17]. The clinical hallmark of patients not presenting with sudden death is a combination of dyspnea and low output symptoms. Other commonly reported symptoms include pain in 78% of patients, depressed mood in 59%, insomnia in 45%, anxiety in 30%, anorexia in 43%, constipation in 37%, and nausea and vomiting in 32% [18].

Patients dying of HF either do so suddenly, suffer a chronic, slow deterioration punctuated by acute episodes, or both. In either case, there is little to no time for the physician to explore patient preferences in this population unless this is addressed early in course of the disease.

### Improving communication

Interviews conducted in Great Britain with patients dying of HF and their caregivers identified several problems unique to the treatment of this patient population [14]. Patients tended not to recall receiving any written

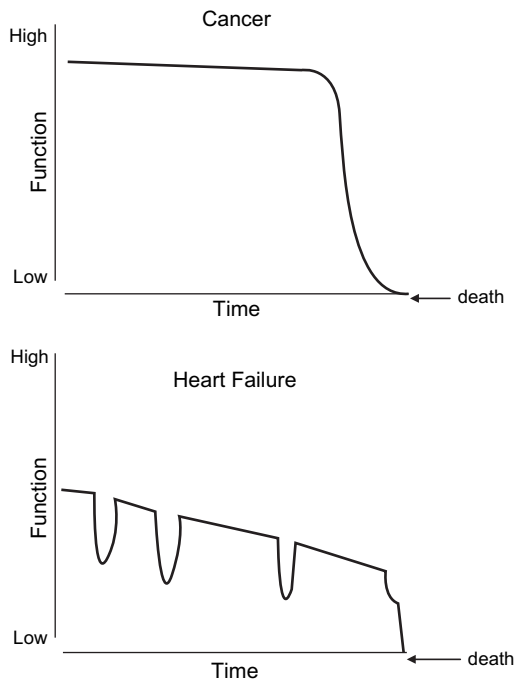


Fig. 1. Typical trajectory of disease for patients who have cancer and heart failure. Top: Patients who have cancer have a long period of preserved function followed by a precipitous drop that starts within a few months before death. Bottom: Patients who have heart failure have an overall gradual decline in function punctuated by periods of exacerbations with acute drops in function followed by a return to near their previous level. (From Goldstein NE, Lynn J. Trajectory of end-stage heart failure: the influence of technology and implications for policy change. *Perspect Biol Med* 2006;49(1):10–9, Fig. 1; with permission. © The Johns Hopkins University Press. Reproduced with permission of the Johns Hopkins University Press.)

information about their condition and often did not see an association between symptoms, such as dyspnea and edema, and their cardiac status. Similarly, patients and caregivers did not feel particularly involved in the decision-making process regarding the illness. Medication regimens were seen as difficult and burdensome despite their frequent effectiveness. The concurrent presence of comorbidity in this generally elderly population added to the burden of the primary condition. Care often was seen as fragmented, with an absence of the kinds of resources frequently available to cancer patients.

Although identification of these problems is helpful, solutions are not necessarily obvious. Initially published a decade ago, the SUPPORT study of the care of patients who have life-threatening diagnoses documented that only 47% of physicians were aware of their patients' wishes regarding cardiopulmonary resuscitation, that 50% of patients reported severe pain at least half the time, and that 38% of patients spent 10 or more days in intensive care [19]. A subsequent intervention that provided written prognostic reports and written synopses of patient preferences regarding resuscitation and pain control for the physicians and a skilled nurse practitioner who monitored the patients' progress resulted in no measurable difference in any of the indices related to communication or outcome [20]. A post-hoc analysis of 236 patients dying of HF in the databases of the SUPPORT trial and the Hospitalized Elderly Longitudinal Project (HELP) databases documented breathlessness in 65% of patients and severe pain in 42% during the last 3 days of life, whereas 40% received a major therapeutic intervention during the same time period [21].

These data clearly speak to the necessity for more robust interpersonal communication and more creative ways of providing services to this patient population. In an intervention conducted at six centers in the United States, 988 terminally ill patients (of whom 21% had heart disease) and 893 caregivers were offered a structured interview [22]. Areas surveyed included questions about symptoms, communication with health care providers, spiritual and personal meaning of dying, care needs, end-of-life plans, economic burdens, preferences regarding end-of-life care, and opinions about euthanasia and physician-assisted suicide, among others. Each respondent also was asked how stressful and how helpful the interview had been. Of the patients responding, 88.7% reported little or no stress associated with the interview, whereas 46.5% thought the interview was somewhat or very helpful. Of the caregivers responding, 89.7% reported little or no stress associated with the interview, whereas 53.4% thought it was somewhat or very helpful. This finding would suggest that the SUPPORT investigators did not go far enough in designing the intervention that was ultimately studied. The use of a more structured interview format with patients and family members might serve to improve communication initially between these individuals and their caregivers and to set the stage for more focused and interactive palliative care.

## Palliative care in heart failure

The previously described uncertainty regarding the trajectory of terminal HF can induce what has been termed a “prognostic paralysis” regarding the initiation of discussion about palliative care and its actual implementation [23]. One commentator has suggested that patients who have HF should be considered candidates for palliative care if a clinician answers “no” to the question, “Would I be surprised if my patient were to die in the next 12 months?” [24]. Another suggested algorithm would initiate palliative intervention during or shortly after recovery from an acute exacerbation of HF [25]. What seems clear from the experience of many is that palliative care needs to be considered much earlier in the course of the disease process than is currently the case.

The hallmark of congestive failure is dyspnea. The initial management of dyspnea in this patient population includes standard management with diuretics, vasodilators, and positive inotropes as necessary. Refractory pleural effusions can be addressed by thoracentesis. Severe dyspnea that remains refractory to these interventions often can be palliated in the opioid-naïve patient with doses of intravenous morphine of between 2 and 5 mg administered intravenously every 5 to 10 minutes as necessary for relief. Low doses of diamorphine (1 to 2 mg) administered as an intravenous bolus have been documented to improve cardiopulmonary exercise test results even in patients who have stable HF [26]. The use of supplemental oxygen and appropriate room ventilation are also helpful.

As noted above, pain is reported in nearly 80% of patients dying of HF, whereas 41% of patients dying of HF in the SUPPORT database had moderate to severe pain during the last 3 days of life [27]. One half of these patients reported moderate to severe pain during the last 6 months of life. Treatment of pain with nonsteroidal anti-inflammatory agents in the setting of HF is relatively contraindicated because of their propensity to retain sodium and to antagonize the effect of ACE inhibitors and decrease renal function [28]. Doses of opioids similar to those effective for dyspnea are often effective for pain control in this population.

Fatigue is often a result of low output and responds to therapy with positive inotropic agents except in the very end stage of HF. Fatigue also may be related to coexistent depression, which usually is best treated pharmacologically with selective serotonin reuptake inhibitors; however, use of these agents in the absence of appropriate psychological, spiritual, and social support is often compromised by noncompliance.

Treatment of comorbidities also may be helpful. The use of continuous positive airway pressure in patients who have sleep apnea secondary to HF has been demonstrated to have no effect on survival; however, reductions in apnea and norepinephrine levels have been documented along with increases in nocturnal oxygen saturation, ejection fraction, and distance walked in 6 minutes [29]. Similarly, treatment of anemia in patients

who have New York Heart Association class II to IV HF with darbepoetin alfa has been demonstrated to improve walking distance and quality of life indicators [30]. Additional comorbidities frequently documented in this patient population that require intervention include chronic obstructive pulmonary disease, arthropathies, and diabetes mellitus [31].

Patients who have HF may benefit from group visits in which palliative care issues can be addressed. A randomized study of 321 elderly patients, 33% of whom had heart disease, demonstrated that patients who received monthly group visits with their primary physician and a nurse that included health education, prevention strategies, opportunities for socialization, and mutual support had fewer emergency department visits, fewer visits to subspecialists, and fewer repeat hospital admissions compared with a control population [32]. The Heart Failure Society of America provides monographs on several related topics, including advance care planning and feelings about HF, that can serve as discussion aids [33,34].

Patients who have end-stage HF suffer from a wide variety of other problems, including the distress of living with a chronic, fatal condition; the disruption of social life, personal goals, income, faith, and daily function; and an increasing dependence on others with a reciprocal loss of self esteem [35]. As many as 60% of patients in one observational review felt that one or more of their problems were inadequately addressed [31]. Identification of these issues was easily facilitated by asking the simple question, "What are your three most troublesome problems?"

People dying of HF also have been documented to have spiritual needs that are characterized by feelings of hopelessness, isolation, and altered self image [36]. Among their concerns are the meaning of life, physical needs and practical problems of living both at home and in social settings, feelings of abandonment by the health care system, loss of dignity, changes in relationships, increasing dependence, and wishes for death. Responses to problems such as these include discussion of life goals and life closure issues, discussion of the meaning of the illness and its attendant suffering, discussion of coping ability, and the involvement of pastoral care services [35].

In many instances support services may be facilitated best by a dedicated palliative care team that has significant experience with dying patients [37]. It is now common for hospice services to accept patients who have HF for the provision of integrated services in both inpatient and outpatient settings [38].

### **Device therapy**

The increasingly common use of device therapy has significantly reduced the morbidity and mortality associated with HF. Notwithstanding, these devices pose significant problems for the end-stage patient who may wish to minimize or reduce the intensity of his or her care. The right of a patient who has intact decision-making capacity to refuse any and all medical

interventions has a long and established history in bioethics and common law [39,40]. This right applies equally to the withholding and withdrawing of therapy and clearly extends to deactivation of pacemakers and defibrillators, each of which constitutes a highly technical medical intervention. In recognition of this, discussion of device inactivation for patients who have HF at the end of life has recently been codified as a Class 1 recommendation in the 2005 update of the American College of Cardiology/American Heart Association guidelines for the management of chronic HF [41]. For patients who lack capacity, all jurisdictions have procedures for identification of an appropriate surrogate decision-maker or documentation of previously expressed health care wishes [42]. Hospitalized patients in the United States are required by law to have information recorded regarding the presence or absence of an advance directive at the time of admission and hospitals are also required to offer the opportunity for the patient to create an advance directive [43]. Notwithstanding this requirement, a recent survey of the next of kin of 100 patients dying with indwelling cardioverter defibrillators revealed that possible deactivation of the devices had been discussed antemortem in only 27 cases, whereas 8 patients were defibrillated by their device only minutes before death [44]. This situation is unfortunate given that deactivation of an implanted defibrillator has been equated to the withdrawal of other technically complex medical interventions, such as hemodialysis, a situation in which consensus has emerged that discontinuation at the request of a patient or recognized surrogate is the appropriate moral response [45].

Unlike cardioverter defibrillators, cardiac pacing, even with biventricular resynchronization, has not been shown clearly to prolong life [46]. One recent randomized, intention-to-treat trial has documented a significant reduction in all-cause mortality associated with cardiac resynchronization compared with medical therapy alone [47]. Another randomized comparison of medical therapy with both resynchronization and resynchronization with an indwelling defibrillator has demonstrated a modest reduction in death because of pump failure with cardiac resynchronization alone; however, the overall effect was negligible because of the increased prevalence of sudden death in the absence of coexistent ICD therapy [48].

Regardless of its effect on life expectancy, there is no question that a primary benefit of cardiac pacing in the patient who has HF is symptom relief. As a result, it is to be expected that informed requests for deactivation of cardiac pacing will be less frequent than those for deactivation of a defibrillator. Patients and surrogates who request deactivation need to be counseled appropriately regarding the potential negative effect this decision may have on the quality of the patient's remaining life. Additional adjustments in timing to optimize AV and VV delay using echocardiography are also helpful for relieving the symptoms of end-stage HF [49]. Should a patient or surrogate still prefer that the device be inactivated, it is important to emphasize that it can be reactivated should the extent of symptomatic deterioration

be unacceptable. Notwithstanding these concerns, pacemaker therapy, including resynchronization, has been withdrawn in patients who were clearly end stage who had no obvious exacerbation of already existent severe symptoms [50]. The informed wishes of patients and surrogates who wish that device therapy be terminated need to be taken seriously and honored. Physicians who find this at odds with their own moral reasoning are not obligated to deactivate a device personally, but are obliged to inform the patient or surrogate of their objection and facilitate a transfer of care to a physician willing to accede to this request [50].

### **Cardiopulmonary resuscitation**

Cardiopulmonary arrest, as an isolated episode, is not uncommon in patients who have HF and does not, in and of itself, portend end-stage disease [6,51]. This may account for the observation that only 23% of patients who had HF in the SUPPORT database initially preferred not to be resuscitated in the event of an arrest [52]. It probably also underpins the relatively high percentage of patients (14%) who changed their preference in favor of resuscitation during the course of their hospitalization. Those who did not want to be resuscitated were older, in higher income brackets, had lower activity status in the 2 weeks before admission, and perceived their prognosis to be worse than those who opted in favor of resuscitation. Although the numbers are too small for accurate comparison, a preference not to be resuscitated seems to have some degree of prognostic significance in and of itself. Of 19 patients subjected to cardiopulmonary resuscitation (CPR) who had expressed a preference for it, 10 were discharged alive. Of 6 patients subjected to CPR who had expressed a preference against it, only 1 survived to discharge [52]. One of the reasons that the numbers are not more robust is that the event rate in hospital in this patient population was only 4%, with most sudden death in patients who had HF occurring out of the hospital [51].

All of this simply confirms that the prognosis of patients who have HF remains variable and rapidly changeable such that decisions regarding resuscitation status, just as all medical decisions for these patients, need to be revisited frequently as clinical status changes.

For those patients who have not expressed a prior objection, recent data have suggested that family members prefer to be present during a resuscitative effort if possible, and that the presence of family members in this context is not usually disruptive [53,54]. As a result, recommendations that family members be offered the opportunity to be present during a resuscitative effort are now included in both the current American College of Physicians Ethics Manual and the American Heart Association Guidelines for Cardiopulmonary Resuscitation and Emergency Cardiovascular Care [40,54].

## Palliative sedation

Patients at the very end stages of pump failure not uncommonly present with hallucinations, delirium, myoclonic jerks, and sometimes seizures that frequently exceed the capability of nonpharmacologic measures for control. Hallucinations and delirium can be pharmacologically managed in many situations with small doses of haloperidol, olanzapine, or risperidone [55]. For those patients in whom delirium is not controlled and for those who present with myoclonus and frank seizures, sedative therapy may be necessary. Commonly used medications for this purpose include midazolam, lorazepam, and propofol [55,56]. Use of these agents in this context has been termed palliative sedation.

The use of palliative sedation has given rise to a large volume of medical literature as a result of its threefold consequences of relief of suffering, removal of consciousness, and potential to shorten life, particularly in patients who have HF who commonly suffer from a combination of hypotension and reduced cardiac output. The appropriate use of palliative sedation has been justified by two commonly used ethical principles: double effect and proportionality. Double effect recognizes that a single action can have both positive and foreseen negative effects. It requires that the agent intend the positive effect, that the action itself not be morally wrong independent of its consequences, that the positive effect cannot be accomplished solely by means of the negative effect, and finally that there be proportionality between the intended and unintended effects [56].

In the case of palliative sedation, the intention is understood to be the relief of symptoms rather than a hastening of mortality. Sedation itself is not considered immoral independent of its consequences and the positive effect of symptom relief is not achieved in and of itself by the foreseen negative effect of a potentially shortened lifespan. Finally, the positive benefit of symptom relief is considered to outweigh the potentially negative effects of additional hypotension and further fall in cardiac output.

It has been argued that this kind of reasoning depends overmuch on the intention of the agent, a factor that is difficult to observe, let alone measure [57]. The difficulty of assessing adherence to the rule of double effect is suggested by a survey of physicians and nurses caring for 44 terminally ill patients in two hospitals in whom life support was being withdrawn [58]. Fully one third of physicians responding identified both the relief of pain and hastening of death as their primary intentions in prescribing palliative sedation. Proponents of the rule argue in response that the simple fact that people can have more than one intention does not invalidate the rule. It is also possible that the physicians in question who intend to hasten death do not consider this intention wrong. Under these circumstances, they do not need to appeal to the rule for justification of their actions because their decision is based on the assumption that the hastening of death is not fundamentally wrong [59,60].

Opponents of the use of the rule of double effect also argue that physicians are and should be held accountable for all foreseeable consequences of their actions rather than simply for those that they intend [61]. As such, some authors argue that the principle of proportionality alone may be a more appropriate justification for the use of palliative sedation [56].

Rendering the ethical landscape more murky still is the principle of collaboration that holds that cooperation in wrongdoing is itself immoral. This cooperation is understood to include advising, assisting, or tempting others to engage in wrongful acts [62]. This creates a morally ambiguous environment for the physician counseling patients or surrogates about potential treatment options when the intent of either the patient or the surrogate is primarily to shorten life, but the physician is morally opposed to euthanasia.

Several caveats are necessary when considering the use of palliative sedation. It is important that all other means of symptom control have been exhausted before its institution and that appropriate consultation with palliative care and pain management specialists have been obtained. Second, it is important that the patient or responsible surrogate is fully informed as to the rationale for palliative sedation and concurs with its use. Third, it is critical that other caregivers on the unit be instructed clearly as to how to proceed with appropriate protocols in place [56].

### **Pitfalls of palliative care**

One perhaps unexpected concern in response to the gradual growth of palliative care initiatives has been the concept of “palliative care triumphalism” [63]. The carefully managed palliative efforts of dedicated professionals, including the use of palliative sedation, run the risk of ignoring the fact that death represents a chaotic disintegration of life that is fundamentally not controllable. To attempt to control it may represent an outright denial of an existential fact of the end of life. One palliative care practitioner has said that, “despite all we might say and all we might do, the process of dying includes suffering and painful separations and unfinished business. Death cannot be tamed. Death is unknown. Death is other. Death is death.” [64].

This observation dovetails into previously identified components of a “good death” as perceived by multiple observers, including physicians, nurses, social workers, chaplains, hospice volunteers, patients, and recently bereaved family members [65]. Only one of the components was pain and symptom management. The other five were clear decision making, preparation for death, completion, contributing to others, and affirmation of the whole person. Implicit in these six components must be the understanding that some of them will come into conflict with others and that this, in and of itself, is not necessarily to be avoided or otherwise palliated.

This understanding was summarized a decade ago in the following fashion: “Often the most effective intervention that we can offer is time spent

with patients and family, listening to concerns and acknowledging their value and touching—a physician's role that is hard to teach and harder to learn in medical education dominated by subspecialist- and procedure-oriented medical centers. We can, at a minimum, heed the powerful lessons taught by experiences with illness and death in our colleagues and loved ones." [66].

## Summary

The terminal stages of HF present challenges to both the patient and the clinician that are the equal of terminal cancer, but with facets that are unique to cardiovascular disease. Among these unique characteristics are prognostic uncertainty, episodes of acute decompensation followed by relatively rapid improvement, and the relative frequency of device therapy. It is clear from the published literature that communication between patients, their family members, and caregivers remains suboptimal and needs to be enhanced through more creative endeavors than have been reported to date. This enhancement includes a more in-depth discussion of the clinical course of HF at an early stage of the illness. Palliative intervention for patients who have HF, including hospice, is clinically indicated for patients presenting with progressively increasing pump failure. Deactivation of device therapy in end-stage patients is often appropriate and needs to be discussed with both patients and appropriate surrogates. Similarly, resuscitation status needs to be reviewed on a regular basis given that preferences regarding resuscitation tend to change frequently in patients who have HF. Palliative sedation is an option for patients who have otherwise uncontrollable symptoms in the throes of end-stage disease; however, careful scrutiny is required to avoid its use in inappropriate situations.

A recent consensus conference identified five questions regarding end-of-life care for patients who have HF that are in need of further research data [67]. How can the physical and psychosocial burdens of advanced HF on patients and families best be decreased? Which patients will benefit from which interventions and how can they be counseled best? Which interventions improve quality of life and best achieve the outcomes desired by patients and family? How can care be coordinated between sites of care and barriers to evidence-based practice reduced? How can prognosis and treatment options be communicated better? These five questions effectively summarize some of the gaps that are currently present in the care of patients who have end-stage HF.

Above all, both the profession and society at large need to reacquaint themselves with the existential reality of death. Confronting this reality for what it is in ourselves, our loved ones, and our patients and their families will help to ensure that our patients are served to the best of our ability, both in their living and in their dying.

## Acknowledgments

The author thanks Daniel P. Sulmasy MD, PhD, OFM and Jane G. McClung PhD for their assistance in the review of this manuscript.

## References

- [1] AGS Ethics Committee. American Geriatrics Society Position Statement: The care of dying patients. *J Am Geriatr Soc* 1995;43:577–8.
- [2] Lamont EB, Christakis NA. Prognostic disclosure to patients with cancer near the end of life. *Ann Intern Med* 2001;134:1096–105.
- [3] Lamont EB, Christakis NA. Complexities in prognostication in advanced cancer. *JAMA* 2003;290:98–104.
- [4] Cowburn PJ, Cleland JGF, Coats AJS, et al. Risk stratification in chronic heart failure. *Eur Heart J* 1998;19:696–710.
- [5] Lee WH, Packer M. Prognostic importance of serum sodium concentration and its modification by converting enzyme inhibition in patients with severe chronic heart failure. *Circulation* 1986;73:257–67.
- [6] Cohn JN, Johnson G, Ziesche S, et al. A comparison of enalapril with hydralazine-isosorbide dinitrate in the treatment of chronic congestive heart failure. *N Engl J Med* 1991;325:303–10.
- [7] Maisel A. B-type natriuretic peptide levels: diagnostic and prognostic in congestive heart failure. *Circulation* 2002;105:2328–31.
- [8] Berger R, Huelsman M, Strecker K, et al. B-type natriuretic peptide predicts sudden death in patients with chronic heart failure. *Circulation* 2002;105:2392–7.
- [9] Watanabe J, Shinozaki T, Shiba N, et al. Accumulation of risk markers predicts the incidence of sudden death in patients with chronic heart failure. *Eur J Heart Fail* 2006;8:237–42.
- [10] Bardy GH, Lee KL, Mark DB, et al. Amiodarone or an implantable cardioverter-defibrillator for congestive heart failure. *N Engl J Med* 2005;352:225–37.
- [11] Daubert JP, Zareba W, Hall WJ, et al. Predictive value of ventricular arrhythmia inducibility for subsequent ventricular tachycardia or ventricular fibrillation in multicenter automatic defibrillator implantation trial (MADIT) II patients. *J Am Coll Cardiol* 2006;47:98–107.
- [12] Bouvy ML, Heerdink ER, Leufkens HGM, et al. Predicting mortality in patients with heart failure: a pragmatic approach. *Heart* 2003;89:605–9.
- [13] Bristow MR, Saxon LA, Boehmer J, et al. Cardiac resynchronization therapy with or without an implantable defibrillator in advanced chronic heart failure. *N Engl J Med* 2004;350:2140–50.
- [14] Weeks JC, Cook EF, O’Day SJ, et al. Relationship between cancer patients’ predictions of prognosis and their treatment preferences. *JAMA* 1998;279:1709–14.
- [15] Murray SA, Boyd K, Kendall M, et al. Dying of lung cancer or cardiac failure: prospective qualitative interview study of patients and their carers in the community. *BMJ* 2002;325:929–33.
- [16] Faber-Langendoen K. A multi-institutional study of care given to patients dying in hospitals: ethical and practice implications. *Arc Intern Med* 1996;156:2130–6.
- [17] Goldstein NE, Lynn J. Trajectory of end-stage heart failure: the influence of technology and implications for policy change. *Perspect Biol Med* 2006;49(1):10–9.
- [18] McCarthy M, Lay M, Addington-Hall J. Dying from heart disease. *J R Coll Phys London* 1996;30:325–8.
- [19] Covinsky K, Goldman L, Cook E, et al. The impact of serious illness on patients’ families. *JAMA* 1994;272:1839–44.
- [20] The SUPPORT Principal Investigators. A controlled trial to improve care for seriously ill hospitalized patients: the study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). *JAMA* 1995;274:1591–8.

- [21] Lynn J, Teno JM, Phillips RS, et al. Perceptions of family members of the dying experience of older and seriously ill patients. *Ann Intern Med* 1997;126:97–106.
- [22] Emanuel EJ, Fairclough DL, Wolfe P, et al. Talking with terminally ill patients and their caregivers about death, dying, and bereavement: Is it stressful? Is it helpful? *Arch Intern Med* 2004;164:1999–2004.
- [23] Stewart S, McMurray JJV. Palliative care for heart failure: time to move beyond treating and curing to improving the end of life. *BMJ* 2002;325:915–6.
- [24] Murray SA, Boyd K, Sheikh A. Palliative care in chronic illness: we need to move from prognostic paralysis to active total care. *BMJ* 2005;330:611–2.
- [25] Hauptman PJ, Havranek EP. Integrating palliative care into heart failure care. *Arch Intern Med* 2005;165:374–8.
- [26] Williams SG, Wright DJ, Marshall P, et al. Safety and potential benefits of low dose diamorphine during exercise in patients with chronic heart failure. *Heart* 2003;89:1085–6.
- [27] Levenson JW, McCarthy EP, Lynn J, et al. The last six months of life for patients with congestive heart failure. *J Am Geriatr Soc* 2000;48(5 Suppl):S101–9.
- [28] Bleumink GS, Feenstra J, Sturkenboom MC, et al. Nonsteroidal anti-inflammatory drugs and heart failure. *Drugs* 2003;63:525–34.
- [29] Bradley TD, Logan AG, Kimoff J, et al. Continuous positive airway pressure for central sleep apnea and heart failure. *N Engl J Med* 2005;353:2025–33.
- [30] VanVeldhuisen DJ, Dickstein K, Cohen-Solal A, et al. Randomized, double-blind, placebo-controlled study to evaluate the effect of two dosing regimens of darbepoetin alfa on hemoglobin response and symptoms in patients with heart failure and anemia. *J Am Coll Cardiol* 2006;47(Suppl A):61A.
- [31] Ward C. The need for palliative care in the management of heart failure. *Heart* 2002;87:294–8.
- [32] Beck A, Scott J, Williams P, et al. A randomized trial of group outpatient visits for chronically ill older HMO members: The cooperative health care clinic. *J Am Geriatr Soc* 1997;45:543–9.
- [33] Heart Failure Society of America. Advance care planning (Module 9). St. Paul: Heart Failure Society of America; 2005.
- [34] Heart Failure Society of America. Managing feelings about heart failure (Module 6). St. Paul: Heart Failure Society of America; 2005.
- [35] Albert NM, Davis M, Young J. Improving the care of patients dying of heart failure. *Cleve Clin J Med* 2002;69:321–8.
- [36] Murray SA, Kendall M, Boyd K, et al. Exploring the spiritual needs of people dying of lung cancer or heart failure: a prospective qualitative interview study of patients and their carers. *Palliat Med* 2004;18:39–45.
- [37] Bailey FA, Burgio KL, Woodby LL, et al. Improving processes of hospital care during the last hours of life. *Arch Intern Med* 2005;165:1722–7.
- [38] Gibbs JSR, McCoy ASM, Gibbs LME, et al. Living with and dying from heart failure: the role of palliative care. *Heart* 2002;88(Suppl II):II36–9.
- [39] Gostin LO. Deciding life and death in the courtroom: from *Quinlan* to *Cruzan*, *Glucksberg*, and *Vacco*—a brief history and analysis of constitutional protection of the “right to die.” *JAMA* 1997;278:1523–8.
- [40] Snyder L, Leffler C. Ethics manual: fifth edition. *Ann Intern Med* 2005;142:560–82.
- [41] Hunt SA, Abraham WT, Chin MH, et al. ACC/AHA 2005 guideline update for the diagnosis and management of chronic heart failure in the adult—summary article. *Circulation* 2005;112:1825–52.
- [42] Gillick MR. Advance care planning. *N Engl J Med* 2004;350:7–8.
- [43] Greco PJ, Schulman KA, Lavizzo-Mourey R, et al. The Patient Self-Determination Act and the future of advance directives. *Ann Intern Med* 1991;115:639–43.
- [44] Goldstein NE, Lampert R, Bradley E, et al. Management of implantable cardioverter defibrillators in end-of-life care. *Ann Intern Med* 2004;141:835–8.

- [45] Berger JT. The ethics of deactivating implanted cardioverter defibrillators. *Ann Intern Med* 2005;142:631–4.
- [46] Braun TC, Hagen NA, Hatfield RE, et al. Cardiac pacemakers and implantable defibrillators in terminal care. *J Pain Symptom Manage* 1999;18:126–31.
- [47] Cleland J, Daubert JC, Erdmann E, et al. The effect of cardiac resynchronization on morbidity and mortality in heart failure. *N Engl J Med* 2005;352:1539–49.
- [48] Carson P, Anand I, O'Connor C, et al. Mode of death in advanced heart failure: the comparison of medical, pacing, and defibrillation therapies in heart failure (COMPANION) trial. *J Am Coll Cardiol* 2005;46:2329–34.
- [49] Bax JJ, Abraham T, Barold S, et al. Cardiac resynchronization therapy: Part 2—Issues during and after device implantation and unresolved questions. *J Am Coll Cardiol* 2005;46:2168–82.
- [50] Mueller PS, Hook CC, Hayes DL. Ethical analysis of withdrawal of pacemaker or implantable cardioverter-defibrillator support at the end of life. *Mayo Clin Proc* 2003;78:959–63.
- [51] Stevenson LW. Rites and responsibility for resuscitation in heart failure: Tread gently on the thin places. *Circulation* 1998;98:619–22.
- [52] Krumholz HM, Phillips RS, Hamel MB, et al. Resuscitation preferences among patients with severe congestive heart failure: results from the SUPPORT project. *Circulation* 1998;98:648–55.
- [53] Tsai E. Should family members be present during cardiopulmonary resuscitation? *N Engl J Med* 2002;346:1019–21.
- [54] 2005 American Heart Association guidelines for cardiopulmonary resuscitation and emergency cardiovascular care—Part 2: Ethical issues. *Circulation* 2005;112(Suppl IV):IV6–11.
- [55] Casarett D, Inouye S. Diagnosis and management of delirium near the end of life. *Ann Intern Med* 2001;135:32–40.
- [56] Lo B, Rubenfeld G. Palliative sedation in dying patients: “We turn to it when everything else hasn’t worked.” *JAMA* 2005;294:1810–6.
- [57] Quill TE, Dresser R, Brock DW. The rule of double effect – a critique of its role in end-of-life decision making. *N Engl J Med* 1997;337:1768–71.
- [58] Wilson WC, Smedira NG, Fink C, et al. Ordering and administration of sedatives and analgesics during the withholding and withdrawal of life support from critically ill patients. *JAMA* 1992;267:949–53.
- [59] Sulmasy DP, Pellegrino ED. The rule of double effect: clearing up the double talk. *Arch Intern Med* 1999;159:545–50.
- [60] Sulmasy DP. Double effect: Intention is the solution, not the problem. *J Law Med Ethics* 2000;28(1):26–9.
- [61] Brody H. Causing, intending, and assisting death. *J Clin Ethics* 1993;4:112–8.
- [62] Jansen LA, Sulmasy DP. Sedation, alimentation, hydration, and equivocation: Careful conversation about care at the end of life. *Ann Intern Med* 2002;136:845–9.
- [63] Barnard D. The skull at the banquet. In: Jansen L, editor. *Death in the clinic*. Lanham, MD: Rowman & Littlefield; 2006. p. 66–80.
- [64] Kearney M. *Mortally wounded: stories of soul pain, death, and healing*. New York: Scribner; 1996. 131.
- [65] Steinhäuser KE, Clipp EC, McNeilly M, et al. In search of a good death: observations of patients, families, and providers. *Ann Intern Med* 2000;132:825–32.
- [66] McCue JD. The naturalness of dying. *JAMA* 1995;273:1039–42.
- [67] Goodlin SJ, Hauptman PJ, Arnold R, et al. Consensus statement: Palliative and supportive care in advanced heart failure. *J Card Fail* 2004;10:200–9.