

THE PRESENT AND FUTURE

STATE-OF-THE-ART REVIEW

How Medicine Has Changed the End of Life for Patients With Cardiovascular Disease



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ABSTRACT

Advances in medicine have changed how patients experience the end of life. With longer life spans, there has also been an increase in years lived with disability. The clustering of illnesses in the last years of life is particularly pronounced in patients with cardiovascular disease. At the end of life, patients with cardiovascular disease are more symptomatic, less likely to die at home, and less likely to receive high-quality palliative care. Social determinants have created widening disparities in end-of-life care. The increasing complexity and duration of care have resulted in an epidemic of caregiver burden. Modern medical care has also resulted in new ethical challenges, for example, those related to deactivation of cardiac devices, such as pacemakers, defibrillators, and mechanical circulatory support. Recommendations to improve end-of-life care for patients with cardiovascular disease include optimizing metrics to assess quality, ameliorating disparities, enhancing education and research in palliative care, overcoming disparities, and innovating palliative care delivery and reimbursement. (J Am Coll Cardiol 2017;70:1276–89) © 2017 by the American College of Cardiology Foundation.

Advances in modern medicine have had a profound effect on cardiovascular disease (CVD) and its manifestations. As the age-adjusted mortality of CVD has dropped, new challenges have emerged (1,2). The prevalence and disability associated with CVD are rising because of the aging population and the obesity epidemic (3). Hospital discharges attributable to CVD have also increased over time (4). Many more patients survive previously life-threatening events such as acute myocardial infarction, but they live with heart failure (HF), which is expected to rise in prevalence to more than 8 million U.S. adults by 2030 (5). These changes, and others detailed later, require cardiologists and other clinicians to re-evaluate their relationship with patients and their caregivers, particularly as patients approach the end of life. This review summarizes major changes brought about by advances in modern CVD care that affect the end of life and their

implications for patients, caregivers, clinicians, and policymakers.

CHANGES IN MODE OF DEATH IN PATIENTS WITH CVD

Improvements in treatments for CVD have led to significant reductions in both sudden cardiac deaths (SCDs) and nonsudden causes of cardiac death (4). The underlying cause of SCD, however, has changed over the past few decades. Although traditionally, SCDs have largely been caused by ventricular fibrillation and pulseless ventricular tachycardia, non-shockable rhythms, such as asystole and pulseless electrical activity, are increasing in proportion. The proportion of out-of-hospital cardiac arrests in Seattle, Washington that were caused by ventricular fibrillation and pulseless ventricular tachycardia decreased from 61% in 1980 to 40% in 2000, and in



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Milwaukee, Wisconsin, this proportion decreased from 44.8% in 1992 to 23.6% in 2002 (6,7). Neither study found an improvement in overall survival, which could be mediated by this changing underlying etiology. The reduction in shockable rhythms as a proportion of cardiac arrests has also been noted among inpatients (8,9).

Patients with HF comprise one of the groups at highest risk for SCD. However, increased use of medical therapy has led to a 44% reduction in SCD in patients with HF, according to a recent study analyzing 12 clinical trials from 1995 through 2014 (10). This changing mode of death, from SCD to pump failure, is one of the reasons that death and dying have become protracted processes dominating the final years of life of patients with advanced CVD (11).

DISABILITY, COMORBIDITY, AND POLYPHARMACY IN THE LAST YEARS OF LIFE

The past 150 years have seen the most dramatic increase in average life expectancy and maximum life span in human history, with a reduction in age-adjusted mortality for CVD across all age groups (4,12). This success in life span extension, coupled with reductions in fertility rates, has transformed the traditionally pyramidal distribution of the human population into a rectangle (13). Even in the emerging economy of China, by the year 2050, there will be 500 million people older than 60 years of age, accounting for almost one-half the population of that country (14).

Although it had been hypothesized that the same advances that extend life span would also delay the onset of chronic disease, longitudinal data have shown no evidence of such “morbidity compression” (15-17). Factors throughout the span of life influence the extent and duration of disability patients live with (Figure 1). In fact, younger U.S. cohorts now entering older age appear to have increased disability compared with prior groups, a trend driven by poor health in middle age, promoted by factors such as smoking and obesity (18). Therefore, despite greater mean life expectancy, disability-free life among older Americans is similar to that of low-income countries such as Mexico and Costa Rica (19).

Several groups are more likely to experience disability than others. Women have a longer life span than men, but they also spend a greater amount of time living with disability, and this difference increases over time (20). This phenomenon has been referred to as the male-female morbidity-mortality paradox. Older blacks also experience fewer disability-free years than whites, with this disparity particularly pronounced for black women (21).

Medical comorbidities are significant drivers of disability at the end of life for patients with CVD. Chronic disorders, such as hypertension and diabetes, frequently cluster in patients with CVD, and the prevalence of these comorbidities increases with age (22). The increasing burden of medical comorbidities with age is accompanied by rising rates of polypharmacy. The average number of medications taken in a trial of terminally ill patients (mean survival 265 days) was 12.5 (23). Notably, no reduction was noted in average medications as patients approached death.

The combination of disability, comorbidity, and polypharmacy frequently progresses to frailty, a syndrome that increases vulnerability to even minor stressors with reduced physiological reserves (18). This syndrome is particularly pronounced in patients with HF. Almost 40% of Medicare patients with HF have 5 or more noncardiac comorbidities (24). The age-adjusted rate of comorbidities has actually increased in patients with HF over time, with the average number of medications increasing from 4.1 between 1988 and 1994 to 6.4 between 2003 and 2008 (25). Such an increase in prescriptions has been shown to result in an exponential rise in drug-related adverse events (26). Furthermore, many patients with HF also receive devices, such as implantable cardioverter-defibrillators (ICDs) and left ventricular assist devices (LVADs), thus making the care of these patients highly complex.

SHIFT IN DEATH FROM HOME TO HEALTH CARE FACILITIES

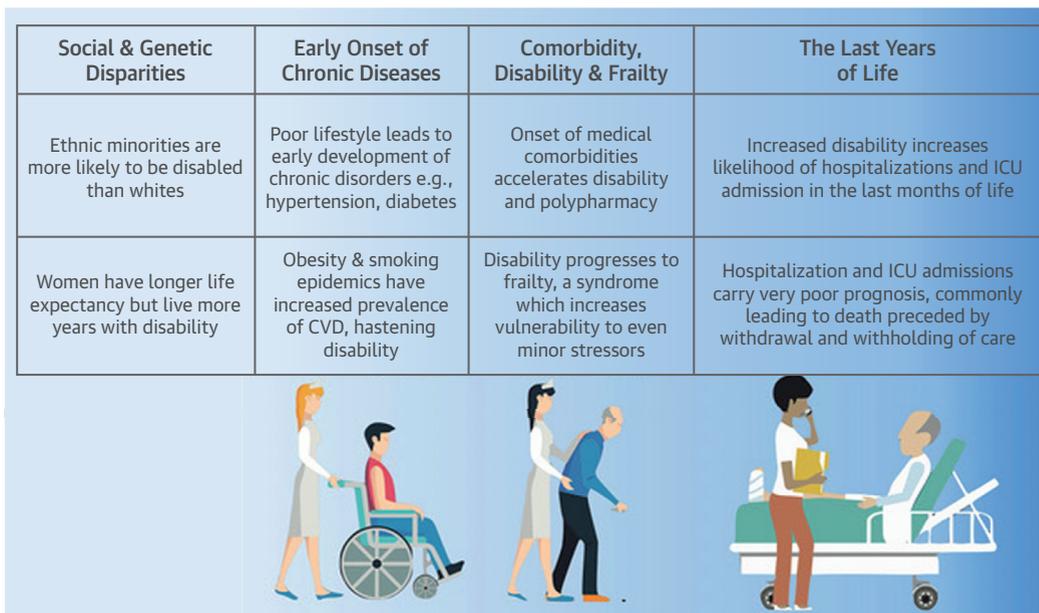
Most deaths in high-income countries occur in health care facilities (27-31). Of patients who do die at home, many are discharged within a week of the hospitalization (32). This trend is in contrast to most patients' preference to die at home (33).

Patients with CVD are more likely than patients with other disorders, such as cancer, to die in the hospital or nursing facility and less likely to die at home (34-36) (Figure 2). This is likely the result of multiple factors. Patients with CVD have an increased symptom burden close to death, a finding suggesting that management of their symptoms at home may be very challenging (37,38). Dyspnea is often a trigger for hospitalization among patients with HF and can frequently lead to patients' dying in the hospital, rather than at home (39). The unpredictable course of HF, punctuated by exacerbations, makes most deaths unexpected for bereaved caregivers (40).

ABBREVIATIONS AND ACRONYMS

- CVD** = cardiovascular disease
- HF** = heart failure
- ICD** = implantable cardioverter-defibrillator
- ICU** = intensive care unit
- LVAD** = left ventricular assist device
- SCD** = sudden cardiac death

FIGURE 1 Progression of Disability and End-of-Life Care



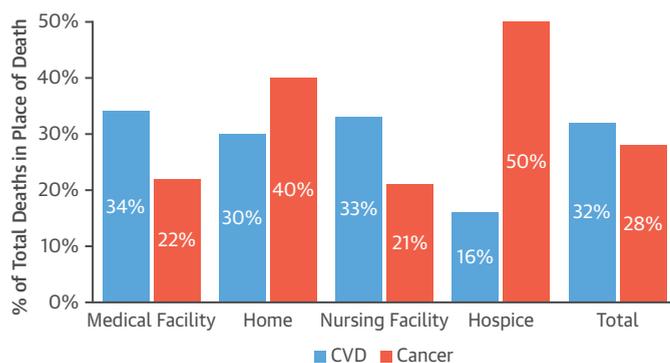
Factors throughout the spectrum of life leading to disability in the last years of life. CVD = cardiovascular disease; ICU = intensive care unit. Created by Freepik.

More than 1 in 5 Americans die in the intensive care unit (ICU), and many older patients with CVD are admitted to the ICU close to the end of life (41). The mean age and severity of illness of patients admitted to ICUs, including cardiovascular ICUs (42), have

increased over time, with CVD remaining the most common reason for ICU admission in the United States (43). The reason for ICU admission for older patients with CVD, however, has changed, with a reduction in acute myocardial infarction, but an increase in cardiovascular organ failure (6% in 1996 and 17% in 2010) (43). However, older patients admitted to the ICU have a very poor prognosis, and there is significant variation in characteristics of patients with CVD who are admitted to ICUs, largely driven by hospital practice patterns, rather than illness severity (44,45). Furthermore, of patients who survive, the number of patients discharged to home and/or self-care after admission to the cardiovascular ICU has dropped from 84% between 1989 and 1991 to 66% between 2004 and 2006 (42). The proportion of patients with HF who are discharged to home or home care after hospitalization has also been reduced from 70% in 1999 to 2000 to 52% in 2010 to 2011 (46).

Recent years have seen a reversal in the trend of deaths in medical facilities and nursing facilities, with an increasing number of patients with CVD now able to die in their homes (Central Illustration). To allow more people to spend time at home toward the end of life, further evolution in the care of patients with CVD is warranted. A recent palliative care intervention in the United Kingdom was shown to increase significantly

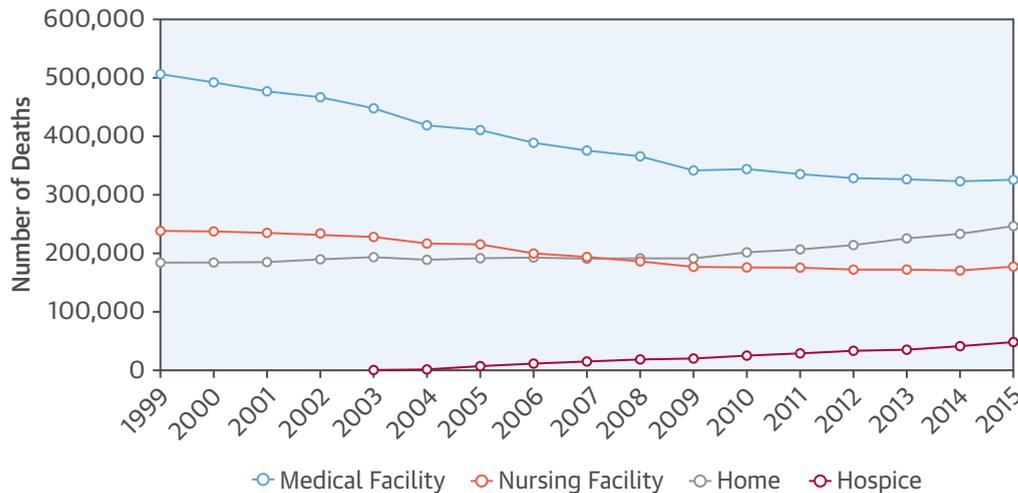
FIGURE 2 Comparison of Site of Death for U.S. Patients Dying of CVD Versus Cancer in 2015



Authors' analysis of Centers for Disease Control and Prevention WONDER (Wide-ranging Online Data for Epidemiologic Research) data with cause of death determined by International Classification of Diseases-10th Revision codes. "Medical facilities" included "Medical facility - inpatient," "Medical facility - outpatient or emergency room," "Medical facility - dead on arrival," and "Medical facility - status unknown." CVD = cardiovascular disease. Data from Centers for Disease Control and Prevention (167).

CENTRAL ILLUSTRATION How Medicine Has Changed End-of-Life Care: Cardiovascular Disease Deaths by Place of Death From 1999 to 2015

U.S. CARDIOVASCULAR DEATHS BY PLACE OF DEATH, 1999-2015



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Authors' analysis of Centers for Disease Control and Prevention WONDER (Wide-ranging Online Data for Epidemiologic Research) data with cardiovascular deaths determined by International Classification of Diseases-10th Revision codes. Hospice death began to be reported in 2003. "Medical facilities" included "Medical facility - inpatient," "Medical facility - outpatient or emergency room," "Medical facility - dead on arrival," and "Medical facility - status unknown." Data from Centers for Disease Control and Prevention (167).

the likelihood that patients with HF would die in their preferred site compared with patients not receiving palliative care (47). Given that adverse events, such as falls, infections, and delirium, are associated with hospitalization, especially for older patients, hospitals are not ideal sites of care for many patients with chronic CVD or those at the end of life (48). A model of care that holds promise is the hospital at home model. If the patient meets specific criteria and voluntarily enrolls in the program, the patient is transported home and has scheduled nurse and physician visits. This program, which includes patients with HF, has been replicated internationally, with a meta-analysis demonstrating a 19% reduction in 6-month mortality rates and improved functional status (49,50). A reimbursement mechanism is now being tested in a Centers for Medicare and Medicaid Services-funded program in New York City (51).

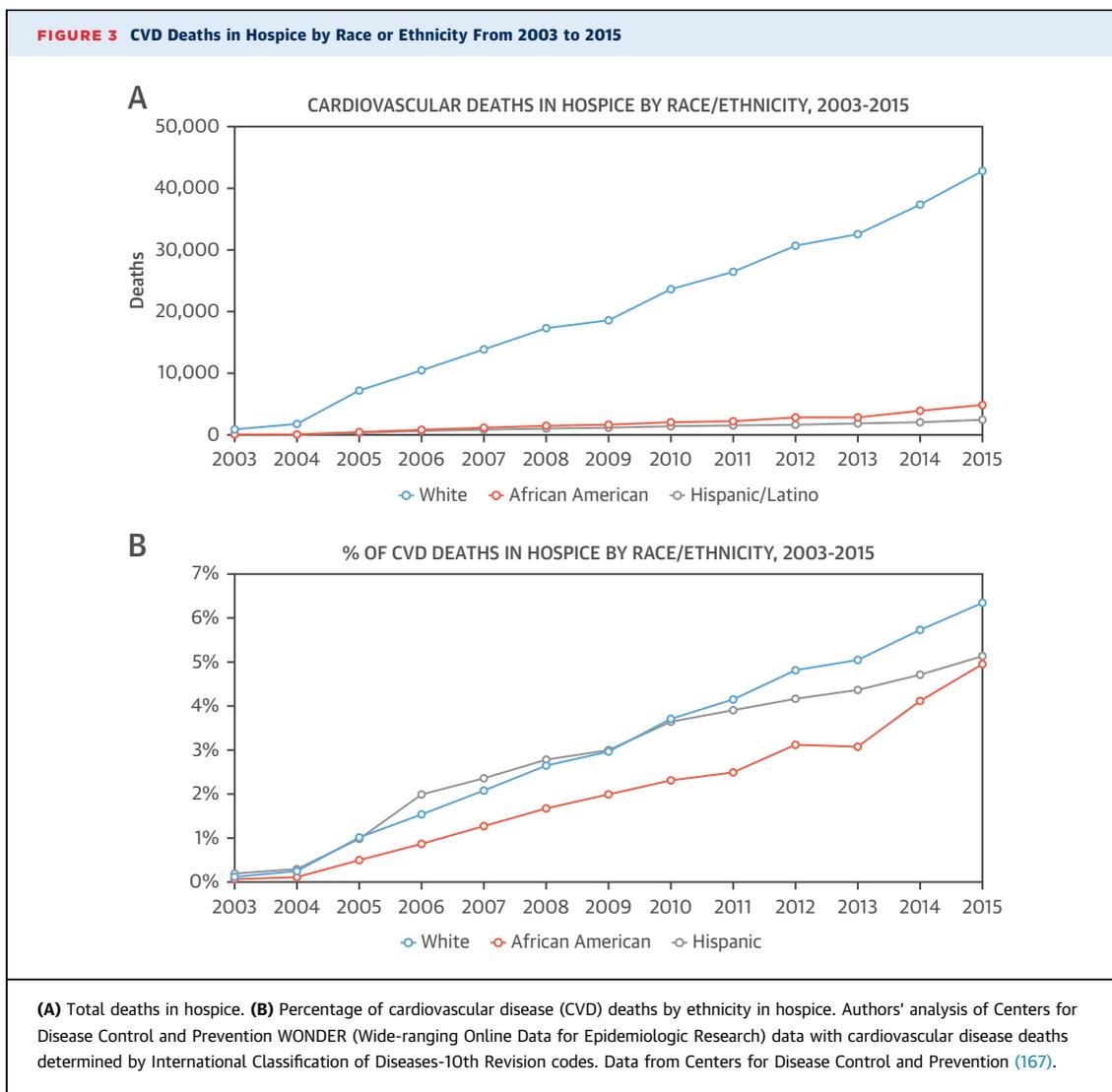
INCREASING DISPARITIES IN DEATH AND DYING

Social determinants of health, such as socioeconomic status and ethnicity, have significant interactions

with health (52,53). Far from being mitigated, disparities in outcomes by socioeconomic status and ethnicity have been exaggerated by advances in modern medicine (54,55). Socioeconomic status, race, and education were noted to create increased disparity in mortality rates in 1986 compared with 1960 (56). Although these disparities are noted in other developed countries as well, they are particularly noteworthy in the United States (57,58).

CVD is a major driver of increased mortality among ethnic minorities and the socioeconomically disadvantaged (59). Compared with whites and Hispanics, blacks have a higher prevalence of cardiovascular risk factors, such as diabetes and hypertension, and are also less likely to be prescribed statin medications for cardiovascular risk reduction (60,61).

Several factors, including poor access to health care and a healthy lifestyle, perceptible and imperceptible bias and prejudice among health care providers, and educational and socioeconomic disadvantages, have resulted in persistent disparities in African Americans with CVD. These disparities in care are particularly apparent at the end of life. Ethnic minorities and the socioeconomically disadvantaged



are more likely to die in a hospital than at home (62,63). Even individuals who do not belong to an ethnic minority are more likely to die in a hospital if they live in a neighborhood with a large minority population (64). This difference has also widened with time (65-67).

Modern medicine has created an increased need for palliative approaches to complex decision making and withdrawal of medical therapies. Yet palliative care is underused in minority populations, and this is a major driver of disparities at the end of life. Fewer African Americans and Hispanics with CVD die in hospice compared with whites (Figures 3A and 3B). Minorities are also less likely even to use hospice services or sign an advance directive compared with whites (68-70). In patients with HF, nonwhite race is associated with lower use of palliative care and

hospice services (71). Conversely, minorities are much more likely than whites to use intensive care and invasive procedures at the end of life, with the result that African Americans and Hispanics accrue 32% and 57% more health care costs, respectively, than matched whites in the last 6 months of life (72).

CAREGIVER BURDEN AND ITS IMPLICATIONS

Informal caregiving is provided by 1 in 4 adult Americans, and most of these caregivers are women (73,74). They account for 90% of home care delivered, providing upward of \$450 billion dollars in services, and spending an average of 20 h a week providing these services (73,74). As a result, one-fifth of caregivers lose employment and one-third lose most or all of their savings because of their responsibilities (75).

Caregiving can adversely affect the health of those delivering it, a phenomenon called caregiver burden, experienced by 40% of caregivers (74). It comprises symptoms such as anxiety, depression, insomnia, and suicidality and is associated with a higher rate of mortality (76-79). Female sex, lack of education, lower socioeconomic status, lack of choice in assuming the role, increased time spent in caregiving, and quality of premorbid relationship between caregiver and patient are some factors that increase the risk of burden (80-84).

The aging of the population, with the aforementioned increase in years lived with disability, appears to be potentially responsible for the increased recognition of caregiver burden in recent times. In parallel with the increasing absolute numbers of people living with multiple disabilities, low fertility rates mean that there are fewer caregivers available to distribute the work. As patients age, so do their caregivers: the average age of caregivers in the United States is 49.2 years, with 34% of caregivers older than 65 years of age and more likely to have medical ailments of their own (74).

Patients with HF, in particular, have a high symptom burden at the end of life. Caregivers of patients with HF provide between 6.7 and 71.4 h of care per week (85-88) for an average of about 4 years (89). Studies demonstrate that, in addition to the issues discussed earlier, caregivers of patients with HF face other challenges. Caregivers of patients with HF frequently lack understanding about managing HF and the role of factors such as diet (90), and they feel unprepared to manage exacerbations and emergencies (91,92). Poor health literacy (93) and low self-confidence (94) among caregivers can adversely affect patients' ability to care for themselves (95).

The emergence of durable mechanical circulatory support has created an entirely new type of caregiver demand. Caregiving for patients discharged to home with LVADs is more burdensome than the care of heart transplant candidates or recipients (96), and it was found to be comparable in burden to patients receiving mechanical ventilation at home in 1 study (97). Caregivers of patients with LVADs exhibit a very high prevalence of depression at discharge (78%), although this improves over time (33% at 3 months post-discharge) (98). One-fifth of caregivers for patients with LVADs are unable to resume their daily activities or employment (97). One study of caregivers for patients with LVADs showed that more than one-half received no help from others with caregiving; they endorsed increased support from the LVAD team, financial assistance support, and housekeeping

assistance as areas where they could be provided with help (99).

Modern caregiving can be improved, and caregiver burden can be mitigated. In 1 systematic review analyzing interventions designed to support caregivers of patients with HF, 4 of 10 randomized controlled trials were positive (100). Interventions that reduced caregiver burden included mobile health support, nurse-led telephonic coaching sessions, and in-person education sessions. For patients considering LVADs, caregiver burden should be addressed during the decision process (101). Additional platforms, such as social media, need to be better investigated to provide extra layers of support for caregivers and patients with LVADs alike (102). Specialties such as palliative care have a greater focus on those persons connected with the patient and are adept at providing increased support at home. Early referral to palliative care should be sought, particularly for patients with increased needs at home.

ETHICAL CHALLENGES ARISING FROM MEDICAL ADVANCES

Advances in life support have made some patients desire limits on the intensity of care at the end of life. Through advance care planning, patients can appoint health care proxies who can make medical decisions on their behalf when they are incapacitated and can document any limits to therapies they would like to receive, such as cardiopulmonary resuscitation or mechanical ventilation. For patients with advanced CVD, it is recommended that these preferences be revisited at least once annually (103). However, despite such recommendations to initiate advance care planning (104), cardiologists rarely begin end-of-life discussions with their patients (105). Although recent years have seen a modest increase in the prevalence of advance care planning among patients with HF, a study from a tertiary care medical center found that only 14.3% of patients with HF had an advance directive in 2013 (106). Cardiologists need to take a more proactive role in having these important discussions with their patients.

Recent years have seen the "right to die" movement gain increasing prominence (107,108). Many European countries allow physicians to provide lethal prescriptions for terminally ill patients to take on their own lives, a practice referred to as physician-assisted death, whereas some countries allow physicians to administer such lethal prescriptions themselves, a practice referred to as euthanasia (109). Several states, including Oregon, Montana, Vermont,

California, Colorado, and the District of Columbia, have legalized physician-assisted death. Physicians practicing in these states will need to be trained in handling patients' requests for assisted death (110). Surveys, however, show that the majority of both patients and physicians supports physician-assisted death, and active campaigns are ongoing in Massachusetts and New York (111,112).

Life-sustaining measures, which may not be able to provide any discernable benefit in critically ill patients and could therefore be potentially considered futile, are sought by many patients and family members (113). Requests for care considered futile by the treatment team cause a high proportion of conflicts occurring between treating providers and patients and their surrogates (114,115). Such treatments also place a disproportionate economic burden on the health system and cause burnout among nurses and physicians (116-118). However, no consensus on the definition of futile care exists. Although futility policies, which allow physicians to withhold or withdraw procedures and supportive technologies that could be considered futile, are present in most hospitals, these policies are rarely invoked because of fears of legal repercussions (119). However, states such as Texas (120) and organizations such as the American Thoracic Society (121) provide procedural frameworks allowing withdrawal of medical support unlikely to provide physiological benefit.

Almost three-fourths of all patients who die in ICUs in the United States and Europe have some limitation on the intensity of care they receive (122,123). Withdrawal and withholding of treatments and life-sustaining apparatuses occur in the majority of deaths that take place in the hospital. Patients with CVD, however, face some additional challenges. Ethical issues particularly relevant to cardiologists frequently arise pertaining to the deactivation of devices such as ICDs, permanent pacemakers, and LVADs. One-fifth of patients with ICDs receive electric shocks within the last few weeks of their life, with 8% receiving a shock within minutes of their deaths (124), thus causing significant distress to the patient and the caregiver (125). However, few physicians discuss these issues with patients, and few patients recall having these conversations with their physicians (126). Many patients are not even aware that device deactivation is an option (127). Decisions about device deactivation are not present in most patients' advance directives (128), and most hospices do not have a protocol to manage ICD deactivation, even though one-third of Medicare patients with ICDs will receive hospice care (129,130). However, most physicians have been involved in deactivation of ICDs, and most feel

comfortable doing so. Guidelines issued by the Heart Rhythm Society support the patient's right to ask for ICD deactivation and suggest that these discussions begin at the time of device implantation (131). A significant barrier to these discussions may be physicians' overestimation of their patients' knowledge and understanding regarding the indications for ICD placement and the ability to deactivate them (132). The fundamental ethical principle of autonomy, however, allows patients to discontinue even lifesaving therapy, and this principle also applies to patients with permanent pacemakers and LVADs (133). Shared decision making and a discussion of end-of-life considerations is therefore particularly important when discussing implantation of durable cardiac devices.

UNMET NEEDS FOR PALLIATIVE CARE IN CVD

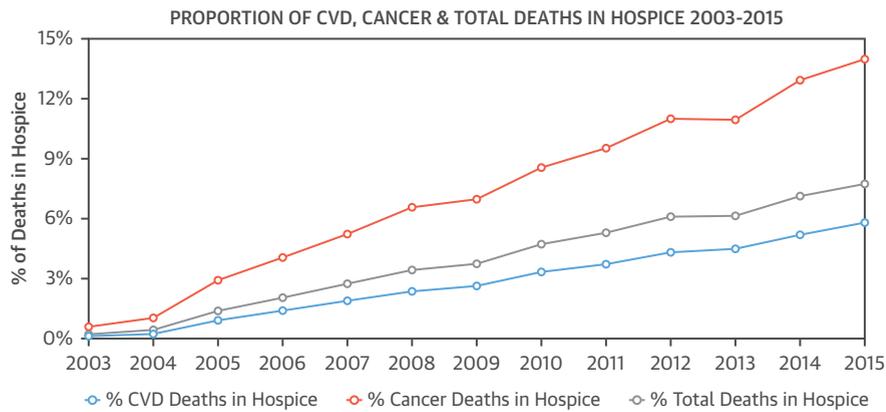
Palliative care is a "multidisciplinary approach to care that focuses on quality of life and a good death" (134), to ease suffering during an increasingly protracted phase of dying (135). It is estimated that three-fourths of patients dying in developed countries do so over a protracted period of increasing disability and thus need palliative care (136).

According to World Health Organization estimates, the population with CVD demonstrates the greatest need for palliative care (137). Although there have been significant increases in the overall use of palliative care in the United States (138,139), the use of palliative care consultations lags in patients with CVD (140). A study analyzing patients dying in Veterans Affairs facilities between 2009 and 2012 showed that palliative care was consulted for less than one-half of all patients who died of cardiopulmonary failure (140). Additional data from the Veterans Affairs health system shows that palliative care consultations increased from about 6% in 2007 to about 10% in patients with severe HF within 1 year of hospitalization (141). Similar low use of palliative care was also demonstrated in a large non-Veterans Affairs population (13.4% of patients seen by palliative care within 1 year of hospitalization in 2014 compared with 5.7% in 2007) (142).

Although hospice use has increased in the number of patients dying of CVD, it too remains underused in patients with CVD compared with the general U.S. population (Figure 4). In 2015, CVD accounted for 32% of U.S. deaths, but only 16% of hospice deaths (Figure 2). Among Medicare inpatients in Alabama, hospice was used by only 8% of patients with HF who died within 6 months of discharge (143).

Patients with HF who do enroll in hospice face additional challenges: The last month of life is

FIGURE 4 Trends in Total, CVD, and Cancer Deaths in Hospice From 2003 to 2015



Authors' analysis of Centers for Disease Control and Prevention WONDER (Wide-ranging Online Data for Epidemiologic Research) data with cause of death determined by International Classification of Diseases-10th Revision codes. CVD = cardiovascular disease. Data from Centers for Disease Control and Prevention (167).

characterized by sharp and unpredictable spikes in symptom burden, unlike in diseases such as cancer that are more predictably progressive (144); this situation results in increased use of acute care services. A large study of Medicare beneficiaries showed that in the last month of life, 60% of beneficiaries went to the emergency room, 64% were admitted to the hospital, and 19% went to the ICU; no reduction occurred in the use of these services between 1997 and 2004 (145). Almost no deaths occurred at home because 39% occurred in the hospital and 60% occurred in nursing homes (145). The unpredictable nature of advanced CVD, punctuated by abrupt and unpredictable declines, leads to very late referral of these patients to hospice. Even among patients with HF who are referred to hospice, the median time from enrollment to death is 12 to 20 days, with 20% to 22% of patients dying within 3 days of enrollment (145-147). This finding emphasizes the need for early referral of patients with HF to palliative care and hospice, given that the recommended and covered duration of hospice services is 6 months.

Aggressive symptom management should be the cornerstone of the management of patients with CVD at the end of life who forego further traditional "curative" therapy. Dyspnea is a cardinal symptom in patients with CVD at the end of life, and a study from 3 community-based palliative care organizations showed that one-fourth of their population with HF had moderately or severely distressful dyspnea (37). Opiates, although traditionally used for pain relief,

cause significant amelioration of respiratory distress (148). However, these drugs continue to be underused in terminally ill patients with CVD (145), even though dyspnea and pain are frequent symptoms in these patients. Medications unlikely to provide symptomatic benefit, such as statins and others that reduce long-term CVD risk, can safely be avoided (149).

Several studies have been conducted evaluating the effectiveness of palliative care interventions on outcomes in patients with HF. A recent systematic review and meta-analysis that included 15 studies (prospective, n = 10; retrospective, n = 5) investigating palliative care interventions in HF demonstrated that the majority of studies showed improvements in quality of life, patient satisfaction, preferences for care, and reductions in metrics of health care use including readmissions (150). However, results were less favorable with regard to increasing hospice enrollment and patients dying at home. Results from the recently published PAL-HF (Palliative Care in Heart Failure) trial showed that patients with advanced HF randomized to receiving a multidimensional palliative care intervention demonstrated improvements in quality of life, anxiety, depression, and spiritual well-being, but not in mortality rates or hospitalizations (151).

A major barrier to the delivery of palliative care to patients with advanced CVD remains the difficulty that physicians face in accurately assessing survival in these patients, with resultant discomfort in engaging in palliative care discussions (152).

FIGURE 5 Improving Care of Patients With CVD at the End of Life

Quality	Disparities	Delivery	Education	Research
Develop both disease-blind and disease-specific metrics	Enhance communication with minorities and low health literacy populations	Consider wider adoption of hospital at home model	Enhance training in palliative care across medical specialties	Prioritize patient centered research
Develop more reproducible and objective metrics	Increase spiritual care for terminally ill patients	Develop alternative models of payments for hospice care	Educate communities and caregivers about death, dying and palliative care	Increase funding for research in palliative care

Recommendations for overcoming challenges in end-of-life care for patients with cardiovascular disease (CVD).

An inability to prognosticate accurately is a major impediment to the appropriate application of palliative care to patients.

OVERCOMING CHALLENGES IN END-OF-LIFE CARE FOR PATIENTS WITH CVD

OPTIMIZE PALLIATIVE CARE QUALITY. To improve the quality of end-of-life care, better metrics are required (Figure 5). Patient satisfaction and family satisfaction are frequently measured, yet current metrics derive from flawed methodology (153). Additionally, although location of death is used frequently, even more important than the location of death is congruence between patients' desired and actual location of death because not all patients wish to die at home (154).

Although some metrics are applicable regardless of disease state, there is a need to develop validated metrics specific to CVD and eventually to report these metrics publicly to spur quality improvement. Specifically for HF, provision of palliative care and decision support consultation at the time of ventricular assist device implantation (155), frequency of annual HF review by clinicians that includes advance care planning (103), and availability of outpatient palliative care services for cardiovascular patients (156) are some of the evidence-based metrics that warrant collection and disclosure.

OVERCOME DISPARITIES IN END-OF-LIFE CARE. How patients interface with death has deep cultural roots, and erasing disparities at the end of life will need medical and nonmedical actions at a societal level. Health systems and medical organizations should partner with communities to develop trust

and change the misperceptions that may exist around modern end-of-life care. Improving communication with minorities should therefore be a priority (157). An additional factor associated with increased reluctance to opt for palliative care among minorities is poor health literacy (158,159). Incorporation of spiritual care is of particular importance with regard to providing holistic end-of-life care, particularly for minority populations (160).

INNOVATE IN PALLIATIVE CARE DELIVERY. Policy makers are deeply interested in improving end-of-life care because more than 8 of 10 Americans who die are Medicare beneficiaries (161). The inclusion of the hospice benefit package by Medicare in 1983 was one of the most significant drivers behind the acceptance of palliative care in the United States (162). In 2016, Medicare introduced several new policy changes to reimbursement for end-of-life care, including adding a billing code for advance care planning discussions, a 2-tiered payment model for hospice patients with low and high use, and Service Intensity Add-on payments for additional services provided for beneficiaries in the last week of life (163). Currently, a demonstration project is under way that allows for hospice patients to receive concurrent curative treatment (164). This pathway would be particularly relevant to patients with HF, who frequently desire simultaneous palliative and supportive therapeutic care (165).

IMPROVE EDUCATION AND RESEARCH FUNDING IN PALLIATIVE CARE. In addition to developing the palliative care workforce, it is imperative that palliative care training be incorporated into the training of cardiologists and additional CVD care providers. Although all terminally ill patients with CVD may not require palliative care referral, identification of a

subset of patients who do is an important skill to recognize. Given that the course of CVD can be unpredictable at the end of life, early referral should be considered for patients and caregivers who could benefit from additional supportive care. Educating the public about palliative care is also important, to overcome misconceptions that can hinder progress in helping patients at the end of life. Palliative care accounts for only 1% of National Institutes of Health support (166). Increased rigor is needed in palliative care research to make interventions generalizable across a variety of clinical settings.

CONCLUSIONS

Advances in medical science have increasingly made health care providers the gatekeepers of death and dying. More patients die of CVD than any other process, and these patients are more likely to die in the hospital with a greater symptom burden than are patients with other disease processes. Care patients receive at the end of life is determined by factors affecting patients throughout their life. Despite our

best efforts, and sometimes because of them, death remains a difficult experience, both from a symptomatic and existential perspective. Although impressive progress has been made, patients with CVD continue to suffer disproportionately. A roadmap is required to develop better tools for predicting survival for patients with CVD, to improve management of their physical and psychological symptoms, and to increase the appropriate use of palliative care for patients with advanced CVD. Understanding how death and dying have evolved is the first step in helping our patients and their loved ones, both at the bedside and on a research and policy scale.

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