

# Palliative Care and Cardiovascular Disease and Stroke

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

**ABSTRACT:** The mission of the American Heart Association/American Stroke Association includes increasing access to high-quality, evidence-based care that improves patient outcomes such as health-related quality of life and is consistent with the patients' values, preferences, and goals. Awareness of and access to palliative care interventions align with the American Heart Association/American Stroke Association mission. The purposes of this policy statement are to provide background on the importance of palliative care as it pertains to patients with advanced cardiovascular disease and stroke and their families and to make recommendations for policy decisions. Palliative care, defined as patient- and family-centered care that optimizes health-related quality of life by anticipating, preventing, and treating suffering, should be integrated into the care of all patients with advanced cardiovascular disease and stroke early in the disease trajectory. Palliative care focuses on communication, shared decision making about treatment options, advance care planning, and attention to physical, emotional, spiritual, and psychological distress with inclusion of the patient's family and care system. Our policy recommendations address the following: reimbursement for comprehensive delivery of palliative care services for patients with advanced cardiovascular disease and stroke; strong payer-provider relationships that involve data sharing to identify patients in need of palliative care, identification of better care and payment models, and establishment of quality standards and outcome measurements; healthcare system policies for the provision of comprehensive palliative care services during hospitalization, including goals of care, treatment decisions, needs of family caregivers, and transition to other care settings; and health professional education in palliative care as part of licensure requirements.

Lynne T. Braun, PhD,  
CNP, FAHA, Chair  
Kathleen L. Grady, PhD,  
MS, RN, FAHA, Co-Chair  
Jean S. Kutner, MD,  
MSPH, Co-Chair  
Eric Adler, MD  
Nancy Berlinger, PhD  
Renee Boss, MD  
Javed Butler, MD, MPH,  
MBA, FAHA  
Susan Enguidanos, PhD,  
MPH  
Sarah Friebert, MD  
Timothy J. Gardner, MD,  
FAHA  
Phil Higgins, PhD, LICSW  
Robert Holloway, MD  
Madeleine Konig, MPH  
Diane Meier, MD  
Mary Beth Morrissey, PhD,  
MPH, JD  
Tammie E. Quest, MD  
Debra L. Wiegand, PhD,  
RN, FAHA  
Barbara Coombs-Lee, PA,  
FNP, JD  
George Fitchett, DMin,  
PhD  
Charu Gupta, MD  
William H. Roach, Jr, JD  
On behalf of the American  
Heart Association  
Advocacy Coordinating  
Committee

**Key Words:** AHA Scientific Statements ■ palliative care ■ quality of life ■ treatment outcome

© 2016 American Heart Association, Inc.

## EXECUTIVE SUMMARY

The mission of the American Heart Association/American Stroke Association (AHA/ASA) includes increasing access to high-quality, evidence-based care that improves patient outcomes such as health-related quality of life (HRQOL) and is consistent with patients' values, preferences, and goals. Awareness of and access to palliative care interventions align with the AHA/ASA mission and goals. Palliative care focuses on communication, shared decision making about treatment options, advance care planning, and attention to physical, emotional, spiritual, and psychological distress with the inclusion of the patient's family and care system in assessment and management. The purposes of this policy statement are to provide background on the importance of palliative care as it pertains to patients with advanced cardiovascular disease (CVD) and stroke and their families and to make recommendations for policy decisions.

Advanced CVD and stroke frequently impose long-term challenges and burden on patients and their families. Patients with advanced heart failure (HF) often experience poor HRQOL, including anxiety, depression, physical disability, and social impairment, as a result of deteriorating health, symptom distress, and complex care regimens. Although offering hope for increased survival and improved HRQOL, advanced treatments such as heart transplantation (HT) and mechanical circulatory support (MCS) also carry risks and limitations. Survivors of stroke and hypoxic ischemic encephalopathy (HIE) often report a lower HRQOL related to life-altering physical and cognitive disabilities, as well as language impairment, emotional lability, and depression. Communication and socialization difficulties are common in pediatric stroke survivors. Caregivers, including parents of children with advanced CVD, struggle to help manage distressing symptoms and other illness effects, complex medication regimens, and equipment. As they try to adjust to physical, emotional, and cognitive changes in their loved one, caregivers often experience psychological stress and significant burden.

Palliative care, defined as patient- and family-centered care that optimizes HRQOL by anticipating, preventing, and treating suffering, should be integrated into the care of all patients with advanced CVD and stroke early in the disease trajectory. Palliative care needs can be addressed by the patient's interdisciplinary care team (primary palliative care), or if appropriate, specialty palliative care providers may be consulted to collaboratively care for patients and their families with more challenging needs. Although recommendations for palliative care in current HF guidelines are increasingly followed by health-care providers, palliative care consultation before and after HT is less common. Of note, inclusion of a palliative care specialist on the MCS team is now mandatory for obtaining The Joint Commission ventricular assist de-

vice (VAD) certification. Specifically, The Joint Commission requires involvement of palliative care specialists for patients undergoing VAD implantation as destination therapy; programs have used this as an opportunity to integrate palliative care into the care of all MCS patients.

Integration of palliative care with the care of stroke patients varies, depending on the extensiveness of the stroke and the stage after stroke, from the acute phase to recovery, long-term rehabilitation, and chronic stroke. Palliative care specialists can work collaboratively with primary treating teams to help patients and families determine treatment goals, discuss prognosis, explore the death and dying process, and discuss hospice and end-of-life care and wishes, in addition to providing symptom relief and emotional and spiritual support and helping patients and families manage functional and cognitive deficits. Importantly, caregivers need and should receive a great deal of support and education from the interdisciplinary care team and palliative care specialists to ease their physical and emotional stress and burden.

Palliative care is an essential health benefit that is central to high-quality overall care. Integrating palliative care in the management of patients with advanced CVD and stroke may provide the following benefits:

- Improved patient and caregiver understanding of disease, treatment, and prognosis
- Improved treatment of symptoms and relief of suffering
- Shared decision making based on patient values, preferences, and goals
- Enhanced patient-clinician communication
- Individual advance care planning based on benefits, risks, and burdens of care
- Improved patient and caregiver outcomes
- Improved preparation for end-of-life and associated care
- Bereavement support

Barriers to the receipt of palliative care by patients include reluctance of providers to refer patients to palliative care as a result of a lack of knowledge about benefits or availability of palliative care services, provider discomfort in communicating with patients and families about palliative care, and limitations in payment systems for comprehensive palliative care services. Congress has introduced legislation related to palliative care in the following areas: advance care planning and advance directives, consumer and family caregiver education and support, professional education and workforce development, payment reform and quality measurement, and reform of the Medicare Hospice Benefit. Recent changes by Medicare to pay for advance care planning services may help to make progress in reducing these barriers.

The AHA/ASA convened a panel of experts to assist the association in developing a set of principles to guide

advocacy efforts related to palliative care. Recognizing that palliative care helps meet the priority needs of patients, better aligns patient care with preferences, supports clinical care best practices, and may contribute to improved quality of care and outcomes for patients and families, the AHA/ASA supports a system of care that does the following:

- Provides patients with access to continuous, coordinated, comprehensive, high-quality palliative care provided simultaneously with specialist-level cardiovascular and stroke care
- Promotes well-prepared, empowered individuals and families
- Customizes care to reflect patient and family preferences and the unique situation of each individual
- Develops and supports a skilled, compassionate, and responsive healthcare workforce
- Embeds and actualizes continual structure and performance assessment based on these principles

On the basis of the guiding principles highlighted above, specific recommendations for policy decisions are outlined in Appendix 1. Recommendations encourage federal and state agencies to reimburse for comprehensive delivery of palliative care services, including palliative care treatment for patients with stroke and CVD. Recommendations support strong payer-provider relationships that involve data sharing to identify patients in need of palliative care, to identify better care and payment models, and to establish quality standards and outcome measurement. Recommendations address healthcare system policies for the provision of comprehensive palliative care services during hospitalization, including goals of care, treatment decision making, needs of family caregivers, and needs associated with transition to other care settings. Finally, these recommendations respond to the need for health professional education and training in palliative care as part of licensure requirements for those who provide care to patients with CVD and stroke, as well as efforts to increase the number of healthcare providers with specialty certification.

## INTRODUCTION

The mission of the AHA/ASA is to help all Americans build healthier lives free of CVDs and stroke. This includes increasing access to high-quality, evidence-based care that improves patient outcomes and quality of life (QOL) and is consistent with patients' values, preferences and goals. Ensuring awareness of and access to palliative care interventions aligns with the AHA/ASA mission and goals. The purposes of this policy statement are to provide background on the importance of palliative care as it pertains to patients with CVD and stroke and their families and to make recommendations for policy decisions

(Appendix 1). Two recent scientific statements by the AHA/ASA, "Palliative and End-of-Life Care in Stroke"<sup>1</sup> and "Decision Making in Advanced Heart Failure,"<sup>2</sup> informed the writing of this policy statement.

According to the *Clinical Practice Guidelines for Quality Palliative Care* by the National Consensus Project for Quality Palliative Care, palliative care is defined as "patient and family-centered care that optimizes QOL by anticipating, preventing, and treating suffering."<sup>3</sup> Palliative care is relevant across the life span, from prenatal to geriatric care, regardless of prognosis. Hospice, on the other hand, provides palliative care for terminally ill patients who have  $\leq 6$  months to live. Of the 20 million people worldwide in need to palliative care at the end of life, 94% are adults and 6% are children.<sup>4</sup>

For the purpose of this statement, primary palliative care is defined as the basic skills and competencies required of all healthcare professionals who care for people with serious illness. Specialty palliative care is defined as the palliative care provided by clinicians with specialty-level training and certification, usually providing consultation in collaboration with the primary treating clinicians.<sup>5,6</sup> Palliative care needs of patients and their caregivers can be met by the primary treating interdisciplinary team and, when needs are more complex, by the integration of palliative care specialists.

Palliative care is team based by its purpose, structure, and function. To address palliative care needs, the healthcare team, patient, and family work together to develop a plan for care that reflects the values, preferences, and goals of the patient. Major foci of palliative care are communication, shared decision making about treatment options, advance care planning, and attention to physical, emotional, spiritual, and psychological distress with the inclusion of the patient's family and care system in assessment and management.<sup>1,2</sup>

## ADVANCED CVD AND STROKE OUTCOMES

Many cardiovascular conditions present acutely or emergently, for example, acute myocardial infarction, cardiac arrest, and acute stroke, and are treatable with procedures, medications, and lifestyle changes. The cardiovascular provider community has become accustomed to successful interventions that treat illnesses and restore functionality. Patients with acute cardiovascular conditions often have palliative care needs such as decision-making support for treatment options.

Chronic cardiovascular conditions, which may start with an acute event, require sustained, lifelong treatment that may slow the progression of the underlying disease but does not cure or stop it. Although these patients may be stabilized with effective treatment, their cardiovascular conditions can impose major long-term burden on patients and their families. In fact, many individuals with

chronic cardiovascular conditions struggle with deteriorating health, symptom burden, or permanent disabilities. It is often these individuals and their families who have significant palliative care needs. The writing committee recognizes that patients with many cardiovascular conditions have palliative care needs, including patients with advanced age and multiple comorbidities, patients who suffer from chronic angina, and patients with frailty or dementia for whom an implantable cardioverter-defibrillator is considered. However, the committee elected to focus on patients with HF, including medical and surgical treatments, and stroke, given the high prevalence and associated morbidity and mortality, highlighting elements of survival, adverse events, HRQOL, and caregiver issues.

## Heart Failure

HF is a chronic condition that is usually progressive and may result in or contribute to the ultimate death of the individual. It affects an estimated 5.7 million Americans  $\geq 20$  years of age.<sup>7</sup> Stage D, affecting  $<1\%$  of patients with HF, is the most advanced progression of HF. Stage D HF is defined as “the presence of progressive and/or persistent severe signs and symptoms of HF despite optimized medical, surgical, and device therapy.”<sup>8,9</sup> Individuals in advanced stages of HF have major functional and lifestyle limitations and may suffer from debilitating symptoms (eg, dyspnea, orthopnea, fatigue, weakness, and anorexia). These patients usually cannot walk 1 to 2 blocks. Among young children with advanced HF, a common symptom is difficulty feeding.

## Survival

As HF progresses, the development of end-organ dysfunction, including renal and hepatic insufficiency and pulmonary hypertension, is common. End-organ dysfunction increases mortality risk and can preclude advanced therapies.<sup>10–17</sup> Elevation of natriuretic peptides, hyponatremia, and worsening renal function all portend a poor prognosis. Submaximal exercise testing also predicts mortality in ambulatory patients with HF.<sup>18</sup> Additionally, cognitive impairment is a predictor of mortality in HF and may affect self-care ability.<sup>19</sup> Social environmental factors such as income, disability status, Medicaid insurance, unmarried status, living alone or at a distance from hospital care, and history of alcohol or drug abuse are independent predictors of poor outcomes, including survival in advanced HF.<sup>20</sup>

In the REMATCH trial (Randomized Evaluation of Mechanical Assistance for the Treatment of Congestive Heart Failure), medically treated adult patients with end-stage HF had a 1-year survival of 25%, and in the INTrEPID trial (Investigation of Nontransplant-Eligible Patients Who Are Inotrope Dependent), survival was 22% at 6 months and 11% at 1 year.<sup>21,22</sup> Another report showed that patients on continuous inotropes had survival of only 6% at 1 year.<sup>23</sup> More recent findings from

the ROADMAP study (Risk Assessment and Comparative Effectiveness of Left Ventricular Assist Device and Medical Management in Ambulatory Heart Failure Patients) demonstrated a 12-month, event-free survival of  $63\pm 5\%$  in New York Heart Association class III/IV, non-inotrope-dependent, medically managed, ambulatory HF patients.<sup>24</sup>

As with other disease states, patients and families tend to overestimate likelihood of survival.<sup>25</sup> Although informing patients of their likely prognosis is important, such predictions are not exact at the individual level, and the notion of uncertainty must enter into the discussion. Pediatric HF outcomes are even more difficult to assess because of their association with a wider range of underlying, typically congenital, causes and prior surgical interventions. Therefore, it is essential that discussions about health status, disease progression, and prognosis begin early in the trajectory of HF.

## Adverse Events

Adverse events occur in patients with HF, especially as HF progresses. The most frequent adverse events in these patients are ventricular arrhythmias, cardiac arrest, renal failure, sepsis, and neurological dysfunction.<sup>21</sup>

## Health-Related Quality of Life

Patients with HF often have poor HRQOL.<sup>2</sup> Patients with advanced HF experience symptom distress, anxiety, depression, a poor health perception, physical disability, social impairment, and poor overall HRQOL.<sup>26–30</sup> The prevalence of depression among adult HF patients is estimated at 22% and increases with worsening symptoms to 42% among class IV patients.<sup>31</sup> Depressed patients with HF have more medication nonadherence, worse health status, and higher healthcare use.<sup>32,33</sup> In the pediatric HF population, feeding problems are common, affecting neurodevelopment and contributing to parental stress.<sup>34</sup> Parents of children who die of advanced heart disease describe that as many as half of children suffer “a great deal” or “somewhat” in the last month of life and that 70% of these children experience a HRQOL in that last month that is “poor” or “fair.”<sup>35</sup>

## Caregivers

Caregivers struggle to manage the myriad symptoms of advanced HF patients in the home.<sup>36</sup> For pediatric patients, these challenges commonly extend to siblings and grandparents. Even in the presence of home-based palliative care, caregivers experience stress, sleep disturbances, and fewer positive experiences because of the unpredictability of HF and the associated physical and psychological challenges in managing the disease.<sup>37–40</sup>

## Heart Transplantation

Although some patients with advanced HF remain on medical therapy, others undergo HT or permanent (ie,

destination therapy) MCS on the basis of medical/surgical and psychosocial/behavioral indications and contraindications. Substantial risks and limitations are associated with these advanced treatments. Both HT and destination therapy MCS are associated with serious complications.<sup>41,42</sup> The likelihood of complications and changes in lifestyle and QOL need to be considered within the context of the patient's life expectancy and with the alternative of remaining on medical treatment. Patients and their families considering these surgical options will benefit from primary palliative care support from the HT and MCS teams and specialist palliative care consultation for advance care planning, goals of care, symptom management, and shared decision making.

### **Survival**

HT has remained the gold standard treatment for end-stage HF since its inception in 1967. Pretransplantation mortality (ie, while on the HT waiting list or after being removed from the list for being too ill) declined from 15.8 deaths per 100 wait-list years in 2002 to 12.4 in 2012.<sup>43</sup> Although the decrease in HT candidate mortality is no doubt due to the use of VADs as a bridge to transplantation, mortality is still high. HT is associated with 1-year survival of 85% to 90% and relief from most, if not all, HF symptoms.<sup>41</sup> Median posttransplantation survival is 11.6 to 12.7 years if the recipient survives the first year.<sup>43</sup>

Median survival for infants after heart transplantation is 20 years but is closer to 12 years for adolescents.<sup>44</sup> Increasingly, these children are considered for second or third transplantations, with worse outcomes each time. Although pretransplantation mortality has declined over the past several years, it is highest for HT candidates <1 year of age, at 53 deaths per 100 wait-list years in 2010 to 2012.<sup>43</sup>

### **Adverse Events**

Long-term complications of HT are common. Patients are at particular risk for cellular rejection, especially during the first year after transplantation, although rates of rejection are lower within the most recent era.<sup>41</sup> They frequently develop coronary artery vasculopathy, which remains the primary reason for retransplantation and death. They also may develop complications from immunosuppression, including infection and malignancy. Medication toxicities may result in the need for kidney transplantation, particularly for children.<sup>44</sup>

### **Health-Related Quality of Life**

Generally, adults experience improved HRQOL from before to early after HT, which is sustained as long as 10 to 20 years after transplantation.<sup>45-47</sup> Children who receive heart transplants do not uniformly report significant improvements in HRQOL, with those transplanted at older ages reporting lowest HRQOL.<sup>48-50</sup> For children, the daily medications and constant surveillance after organ trans-

plantation become particularly challenging as they develop increasing needs for independence and control. However, data suggest that adult survivors of pediatric HT report a good HRQOL.<sup>51,52</sup>

### **Caregivers**

Patients receiving transplants require a great deal of caregiver support, both before and after the transplantation. HT can also be associated with significant financial hardship. Hence, caregiver burden may be high.<sup>53,54</sup> Parents of children who have had heart and other solid-organ transplantations report that these stressors can be mediated by support anticipation from health professionals.<sup>55</sup>

## **Mechanical Circulatory Support**

### **Survival**

Given the limited and relatively static number of donor organs available and the rapid and significant advances in technology, the use of MCS has increased dramatically in the past 10 years. More than 2500 MCS devices were placed in 2014, the highest annual number recorded since the inception of INTERMACS (Interagency Registry for Mechanically Assisted Circulatory Support), the principal registry of MCS.<sup>56</sup> Survival for these patients is estimated to be 80% at 1 year and 70% at 2 years.<sup>56</sup> Outcomes after surgery vary and depend greatly on disease severity preoperatively.<sup>57,58</sup> Use of MCS in children is increasing, and data suggest that MCS can successfully bridge some children to transplantation.<sup>59-61</sup>

### **Adverse Events**

MCS patients are prone to a variety of complications, the most common being infections, stroke, and gastrointestinal bleeding.<sup>56</sup> Patients may continue to have some HF symptoms, particularly related to right-sided HF. Unplanned readmissions for this patient population may approach 50% according to recent studies.<sup>62,63</sup> Thus, resource use in this patient population can be quite high.<sup>64</sup>

### **Health-Related Quality of Life**

HRQOL for most patients with MCS significantly improves postoperatively, although improvement is not similar in all domains of HRQOL.<sup>65</sup> Studies suggest modest improvements in cognitive function, social health, and frailty, but given the severity of illness preoperatively, many patients continue to struggle with these issues postoperatively.<sup>66,67</sup>

### **Caregivers**

Caregivers of patients with MCS often experience significant stress as they take on responsibility postoperatively, including assisting with frequent dressing changes and battery and equipment management.<sup>68</sup> Parents of children with MCS devices exhibit increased levels of depression and anxiety.<sup>69</sup> Some caregivers may struggle

with learning and handling this equipment, which requires manual dexterity and familiarity with technology. There may be a significant amount of psychological stress; caregivers may feel that if they make an error with this equipment they could jeopardize the health of their loved one. Therefore, caregiver burden can be high during the postoperative period.<sup>70,71</sup>

## Stroke

Approximately 6.6 million Americans ( $\geq 20$  years old) have had a stroke.<sup>7</sup> Stroke and HIE after cardiac arrest can cause severe acute brain injury (in addition to traumatic brain injury), which threatens what many people consider their essence.<sup>72</sup> Treatment of and care for patients and families with stroke and HIE often involve multiple providers across many settings: emergency department, intensive care unit, hospital, acute rehabilitation unit, nursing home, and hospice. Survivors of stroke and HIE are often left with life-altering disabilities and limitations despite rehabilitation and effective supportive care. These individuals may confront physical or mental loss and chronic pain and have to deal with uncertainty about additional treatment options and prognosis.<sup>1</sup> Although many of the data and statistics below refer to patients with stroke, similar challenges and approaches also exist for patients who suffer significant HIE after a cardiac arrest.

### Survival

Stroke is the fifth leading cause of death. Stroke accounted for  $\approx 1$  of every 20 deaths in the United States in 2013 and is a leading cause of adult disability.<sup>7</sup> Early deaths caused by stroke and HIE often result from either brain death or a decision not to initiate or to discontinue life-sustaining interventions after a process of shared decision making.<sup>73</sup> When the neurological injury is severe, virtually all communications are through surrogate decision makers, and structured, proactive, and periodic family meetings are essential to ensure optimal decision making and patient- and family-centered satisfaction. Early treatment decisions often include thrombolytic management, surgical options, and approaches to ventilation and nutrition.

### Adverse Events

Patients who do not die as a result of the acute injury enter a recovery stage. Prognosis for recovery depends on numerous factors, the most important of which are initial stroke severity, age, and the presence of comorbidities. This stage of recovery and adjustment is highly variable, requiring patients and caregivers to adapt to new disabilities and social roles. Although the spectrum of functional and cognitive deficits is vast, the extremes of health outcomes include full recovery to severe disabilities affecting both functional and cognitive abilities, for example, vegetative states, minimally conscious states, severe disability, and locked-in syndrome. Depending

on the degree of disability, periodic complications and accumulating comorbidities can lead to sudden or progressive declines in function and cognition. The majority of patients who enter these new states of disability and impairment, however, can find new meaning and happiness during this period of adjustment.<sup>74</sup>

### Health-Related Quality of Life

Stroke patients and families often report lower HRQOL than nonstroke patients, and HRQOL is correlated with the severity of the stroke.<sup>1,75</sup> Particular attention is needed for young children, older patients, and those with impaired communication because they are at highest risk for inadequate assessment and symptom management.<sup>76</sup> Although pain is often not a symptom of acute stroke, up to one half of stroke survivors develop pain within 6 months after their stroke.<sup>77</sup> Common poststroke pain syndromes include central poststroke pain and hemiplegic shoulder pain. In addition to the disabilities commonly associated with stroke (eg, loss of motor function, language impairment), many other symptoms occur and affect HRQOL, including fatigue, incontinence, sexual dysfunction, emotional lability, impaired social functioning, and seizures.<sup>1,75,78,79</sup> Up to one third of patients develop poststroke depression,<sup>78</sup> hence, providers need to be vigilant in its detection and management.<sup>80</sup> Stroke patients also are at heightened risk for anxiety and delirium. Communication and socialization difficulties are common in pediatric stroke survivors.<sup>81</sup>

### Stroke Caregivers

Stroke touches many lives, and caregivers need to adjust and cope with the physical, emotional, and cognitive changes of their loved ones.<sup>82</sup> Parents of children with moderate to severe disability after stroke report increased depression, anxiety, and marital and family discord.<sup>83</sup> Common fears of caregivers result from uncertainty in prognosis, fear of another stroke, and feelings of abandonment.<sup>84</sup> Caregiver support and education are needed but often are not enough, particularly for those with complicated grief reactions.<sup>85</sup> Although data are sparse, stroke can also cause spiritual pain. As a result, providers should identify and manage existential suffering, including referral to a chaplain or spiritual care provider when appropriate.<sup>86</sup>

## ROLE OF PALLIATIVE CARE FOR PATIENTS WITH ADVANCED CVD AND STROKE AND THEIR CAREGIVERS

Palliative care is patient- and family-centered care that optimizes QOL by anticipating, preventing, and treating suffering in multiple domains.<sup>3</sup> Primary palliative care should be integrated into the care of all patients with advanced CVD and stroke.<sup>10,87-89</sup> Palliative care needs must be addressed by clinicians who have the knowledge and skills necessary

to provide seamless palliative care to vulnerable patients and their families. Of particular importance is relief of suffering, provision of comfort measures, and skill with having difficult conversations about advanced illness. A cardiac or stroke interdisciplinary team should not hesitate to engage the assistance of a specialty palliative care team for patients with more challenging issues (eg, complex symptom control, complicated advance care planning, difficult decision making).<sup>5</sup> A shared-care approach to addressing palliative care needs may be appropriate for certain patients.<sup>89–91</sup> This approach combines cardiovascular and stroke treatment with the resources and expertise of a palliative care team. The following sections describe the status and important attributes of palliative care as related to advanced CVD and stroke patients.

### HF and Palliative Care

The American College of Cardiology Foundation/AHA guideline for the management of HF states that “palliative and supportive care is effective for patients with symptomatic HF to improve quality of life.”<sup>10</sup> Guidelines from the Heart Failure Society of America also have multiple recommendations about palliative care, including necessary education of patients and families about QOL, prognosis, risk of death (including sudden cardiac death) despite ongoing active treatment, goals and efficacy of therapeutic plans, and discussions of hospice or end-of-life care and wishes (including explicit discussion of defibrillator deactivation).<sup>88</sup>

### HT and Palliative Care

Although the inclusion of palliative care teams in the provision of care for patients with advanced HF is slowly gaining acceptance, especially for patients who are not HT candidates, palliative care consultation during the evaluation for transplantation, at listing, and postoperatively is less common.<sup>92,93</sup> Palliative care is relevant for patients being considered for HT because these patients have needs for advance care planning and are likely to have needs for symptom palliation and family support.

### MCS and Palliative Care

Except for emergency situations, prospective MCS patients should meet with palliative care providers before MCS implantation to assist them with the decision-making process and to help with their perioperative management. Of note, inclusion of a palliative care specialist on the MCS team is mandated for obtaining VAD certification from The Joint Commission.<sup>94</sup> Although The Joint Commission requires involvement of palliative care specialists for patients undergoing VAD implantation as destination therapy, programs have used this as an opportunity to integrate palliative care into the care of all MCS patients.

The quality of the death and dying process among patients with MCS devices has not been extensively researched, but it is clear that unique challenges exist in caring for these patients. Patients and family members may be asked to make decisions about turning the MCS device off, which often raises ethical and spiritual issues for patients and their caregivers.<sup>95</sup> Hospice can be particularly helpful for this patient population, but hospice providers may require specific training on how to care for patients with MCS. For all of these reasons, it is preferable for MCS programs to work collaboratively with palliative care teams and for these palliative care teams to assist with the transition to hospice when appropriate.

### Stroke and Palliative Care

The palliative care needs of patients and families with stroke are enormous.<sup>1</sup> In the acute stages of stroke, the most important patient and family needs surround decision making under time pressure and uncertainty, developing trusting relationships in a crisis situation, and managing terminal symptoms for those dying in the acute stages. For those in the recovery and chronic stages of stroke, palliative care needs involve adapting to a wide range of functional and cognitive deficits and detecting and managing physical (pain, spasticity) and psychological (depression, anxiety) symptoms that often emerge during the process of rehabilitation.

### Patient and Caregiver Understanding of Disease, Treatment, and Prognosis

It is important that patients with advanced CVD and stroke and their caregivers understand their illness, prognosis, and treatment options. Information should be provided at the time of initial diagnosis and updated and discussed throughout a patient’s illness course. With the patient’s permission, key family members and any appointed healthcare agent also should be included in these discussions. In the case of children, patients themselves should be included in these conversations when they are willing and able to participate.

Providing prognostic information to a patient and his or her family is not a straightforward process. Information needs to be easily understandable.<sup>96</sup> Evidence about what or how patients and families want to be told about prognosis is lacking. However, resources are available that can be used when informing patients and their families about advanced CVD treatment options.<sup>2,97</sup> Providing information on the complexity involved in determining prognosis is important. Patients and their families need to be aware of the variability that can occur in each person’s illness trajectory. Patients and family caregivers have reported that they need help adjusting to and planning for the uncertain illness course.<sup>98</sup> Because informational needs change over time, patient and family education should be viewed

as an ongoing process.<sup>99</sup> Although palliative care specialists may not be best suited to share specific information about CVD, prognosis, and treatment, they have a valuable role in encouraging patient-provider communication, dealing with barriers, and facilitating shared decision making among patients, families, and care teams.

Providers report that the unpredictable disease trajectory often prevents them from discussing future care options and end-of-life issues.<sup>100</sup> However this communication simply must take place. Instead of serving as a reason to avoid conversation, uncertainty should be a trigger for exploration. Poor communication about prognosis and the anticipated course of illness can result in patients receiving more aggressive care and treatments than they really want.<sup>99</sup> Furthermore, the majority of patients with serious illnesses want healthcare providers to initiate and have conversations about goals of care and end-of-life care.<sup>101</sup> These conversations are important and need to occur over time. A good relationship with the patient and family and repeated opportunities for discussion can greatly facilitate communication.<sup>102</sup>

### Shared Decision Making Based on Patient Values, Preferences, and Goals

A palliative care approach embraces shared decision making, the process through which patients and providers share information with each other and work together to make decisions about care and treatment options from medically reasonable options that are aligned with the patient's values, goals, and preferences.<sup>2</sup> Providers need to have open discussions with patients about their values, preferences, and goals. This information will guide care and treatment options for the patient.

### Patient-Clinician Communication

By providing emotional support to families, helping navigate the hospital system, and discussing available care options, palliative care teams have been shown to improve the hospital experience for patients with HF and their families.<sup>103</sup> One critical application of palliative care expertise is enhancing patient-clinician communication, particularly related to goals of care discussions. In an assessment of home-based palliative care, all individuals had at least 1 goals-of-care discussion compared with 41% of individuals in a control group.<sup>104</sup> Goals-of-care and end-of-life discussions have been associated with better patient and caregiver QOL.<sup>105</sup> Having goals-of-care discussions either by the primary care team or through involvement of palliative care specialist consultation may therefore provide an important perspective in the care of chronically ill individuals with frequent episodes of acute illness. Improved understanding of patient preferences and goals of care also results in improved caregiver outcomes. Perceived patient quality of death and the presence of a do-not-resuscitate order are predictive of improved caregiver mental health.<sup>106</sup>

Scientific statements have examined the issue of clinician-patient-family communication and made recommendations for components that should be included in these conversations. The Table is an example of the annual care review for a patient with HF and highlights many of the elements felt to be important by this writing group.

### Advance Care Planning Based on Benefits, Risks, and Burdens of Care

Information about advance care planning should be provided to all patients with advanced CVD and stroke. Patients should be counseled that they have the option to plan in advance for their future health care and that they may formulate advance directives. Patients should also be encouraged to communicate their wishes and share their documents with their identified surrogate decision maker, key members of their family, and their providers. The primary care team and/or specialist palliative care providers need to facilitate these conversations so that the patient, family, and providers clearly understand the patient's current and future wishes.

Advance care planning discussions offer patients the opportunity to define their preferences and expectations for the medical care that they want to receive as

**Table. Selected Components That May Be Included in an Annual HF Review<sup>2</sup>**

Characterization of clinical status
Functional ability, symptom burden, mental status, QOL, and disease trajectory
Perceptions from caregiver
Solicitation of patient values, goals, and general care preferences
Estimation of prognosis
Consider incorporating objective modeling data
Orient to wide range of uncertainty
Review of therapies
Indicated HF therapies in appropriate patients (BB, ACEI/ARB, AA, CRT, ICD)
Treatment of comorbidities (eg, AF, hypertension, DM, CKD)
Appropriate preventive care within the context of symptomatic HF
Planning for future events/advance care planning
Resuscitation preferences
Desire for advanced therapies, major surgery, or hospice
Standardized documentation of the annual review in the medical record

AA indicates aldosterone antagonist; ACEI, angiotensin-converting enzyme inhibitor; AF, atrial fibrillation; ARB, angiotensin II receptor blocker; BB,  $\beta$ -blocker; CKD, chronic kidney disease; CRT, cardiac resynchronization therapy; DM, diabetes mellitus; ICD, implantable cardioverter-defibrillator; HF, heart failure; and QOL, quality of life.

Reprinted from Allen et al.<sup>2</sup> Copyright © 2012, American Heart Association, Inc.



their condition progresses and death nears.<sup>105</sup> A study of patients enrolled in cardiac rehabilitation programs revealed that 96% of patients expressed interest in discussing advance care planning with their physicians, but only 15% had discussed advanced planning with their physicians and 10% had confidence that their physicians understood their end-of-life wishes.<sup>107</sup>

Patients should be advised to designate a healthcare agent through the completion of a healthcare proxy (or a durable power of attorney for health care). Healthcare proxy execution requirements vary from state to state.

It is also important that members of the care team provide appropriate support to patients as their illness progresses, engaging patients in goals-of-care discussions and giving them ample opportunity to complete medical orders for life-sustaining treatment (which has different names in different states, such as physician orders for life-sustaining treatment or medical orders for life-sustaining treatment)<sup>108</sup> based on the patient's current medical condition, values, wishes, and informed consent by the patient or his/her healthcare agent or surrogate.<sup>109</sup> These documents are portable order sets that are written to ensure that care is provided according to patient wishes. These order sets are honored in all settings, including home, acute care, long-term care, and hospice settings, and may include actionable orders concerning patient preferences for cardiopulmonary resuscitation, artificial nutrition and hydration, antibiotic use, other life-sustaining therapies (eg, implantable cardioverter-defibrillators, assist devices), and comfort care. Providers need to be aware of state legislation related to these order sets. If, however, after a relevant examination and discussion with the patient a healthcare provider finds that existing physician/medical orders for life-sustaining treatment are not consistent with the patient's current wishes, the provider should amend the existing physician/medical orders for life-sustaining treatment form to reflect that patient's current wishes.

Pediatric patients (adolescents in particular) should be encouraged to fill out companion documents such as My Wishes, Five Wishes, or Voicing My Choices.<sup>110,111</sup> Although not legally binding, these documents facilitate important discussions with children and teens to allow them a measure of autonomy in participating in their own healthcare decision making.

It is essential to review advance directives with patients at least annually and medical orders if the patient's wishes change, at the time of significant changes in health status, when care transitions are made, and as governed by applicable laws and regulations.

### Patient Outcomes

The inclusion of palliative care services may positively affect CVD and stroke patients' QOL and satisfaction

with care. Although the majority of palliative care and hospice research has been conducted in the cancer population, similar benefits are suggested for patients with advanced CVD.<sup>111</sup> Studies suggest that patients with advanced HF managed with a palliative care team may report improved symptom control with lower total opiate requirements.<sup>112</sup> Patients comanaged by primary and palliative care teams report better QOL (general health, emotional and social functioning) and less depression than their counterparts, as shown in a study of women treated for advanced breast or gynecological cancers.<sup>113</sup> A study surveying patients enrolled in one hospice program reported good or very good QOL during their admission, although this was not always the case at initial presentation.<sup>114</sup>

Additionally, patients may live longer when palliative needs are considered during the course of their chronic illness. HF patients enrolled in hospice have been found to have longer survival than those not enrolled in hospice.<sup>115</sup> Although patients have higher rates of live discharge from hospice, services remain underused in this population.<sup>116</sup>

### Caregiver Outcomes

Because palliative care and hospice can provide additional resources and support, incorporation of palliative care or hospice can ease caregiver burden.<sup>117,118</sup> In a qualitative study of bereaved caregivers of cancer patients, caregivers recommended that palliative care is introduced when patients have uncontrolled symptoms or require assistance at home, further emphasizing the need for additional resources at these time points.<sup>119</sup> Additional efforts to individualize support may more appropriately address caregiver strain.<sup>120</sup>

Caregivers of patients with HF noted that their personal health was compromised after recent patient hospitalizations, demonstrating the impact of patient outcomes on caregiver outcomes.<sup>121</sup> Thus, frequent hospital readmissions or perhaps worsening of a patient's condition leading to hospitalization may result in caregiver distress and a negative impact on caregivers' health.

Even after a loved one's death, caregivers may question or regret treatment decisions, location of death, or quality of death. Patient death in the critical care setting has been associated with increased risk of posttraumatic stress disorder and complicated grief in caregivers compared with home hospice deaths.<sup>122</sup> Caregivers who believed that their loved ones died in their preferred location were more satisfied with the patient's end-of-life care.<sup>123</sup> Efforts must be made to elicit patient preferences early in the disease course. The early elicitation of patient preferences may be especially important in the CVD population, considering the numerous options for diagnostic testing and advanced therapies even in end-stage disease.



Although the direct impact of hospice care on caregiver QOL remains uncertain, a relationship between caregivers' QOL and their estimate of the patients' QOL was shown when cancer patients received hospice services.<sup>124,125</sup> Limited and conflicting evidence supports the ability of palliative care programs to reduce burden among caregivers of patients with advanced HF.<sup>126,127</sup> Abernethy et al<sup>120</sup> found that bereaved caregivers of patients receiving specialized palliative care services for a terminal illness were more likely to report having "moved on" after the loss of their loved one. Conversely, several other studies of palliative care interventions for many diseases have failed to demonstrate significant reduction in caregiver burden or improvement in QOL.<sup>128-131</sup>

### Preparation for End-of-Life and Associated Care

CVD and stroke patients and families need to be prepared for what to expect near the end of life. Palliative care experts can help patients, families, and other providers prepare for this phase. Care at the end of life is focused on the prevention and management of distressing symptoms, with a focus on pain, dyspnea, and anxiety. The goal of care is to support a peaceful death for the patient and to provide support for the family.<sup>132</sup> Referral to hospice care under the Medicare Hospice Benefit can be made when the patient's life expectancy is estimated to be  $\leq 6$  months if the disease follows its normal course. Hospice care offers in-home visits, access to requisite medications and equipment, emergency hotlines, inpatient hospice care, and relief and support for family members.<sup>133</sup> Despite the availability of hospice care, most patients dying of advanced CVD die in hospitals.<sup>134</sup>

End-of-life care for patients with advanced CVD often involves decisions to stop or deactivate devices, including implantable cardioverter-defibrillators and VADs. Before deactivating cardiac devices, patients and family members need to understand the patient's condition and care options and have clear knowledge of what will happen if the device is stopped (eg, anticipated death).<sup>135</sup> Protocols need to be in place to guide nurses and physicians as devices are withdrawn.<sup>136-138</sup> Conflicts that may arise in connection with these decision processes may be referred to institutional ethics committees.

### Bereavement Support

The World Health Organization and the National Consensus Guidelines identify the patient's family as requiring support in bereavement.<sup>3</sup> Because caregivers may experience depression, major depressive disorder, complicated or prolonged grief, or even posttraumatic stress disorder, the period after a patient's death remains an important part of the illness experience.<sup>121,139</sup> However, traditional healthcare systems do not incorporate the caregivers' health into the scope of practice. For example, palliative care specialists are more likely to provide

bereavement follow-up than oncologists.<sup>140,141</sup> Hospice services offer bereavement care for up to 1 year after the death of a patient (sometimes longer for pediatric patients). It is essential that providers who had supportive relationships with the deceased patient and his or her family members develop systems for supporting surviving family members during their bereavement.

### Barriers to the Receipt of Palliative Care

Direct care providers often play the critical role of ensuring that patients receive palliative care. However, providers may be reluctant to offer palliative care, may not recognize which of their patients could benefit from these services, or may not be aware of the availability of palliative care services in their setting or community.<sup>142</sup> Providers may also be uncomfortable communicating with the patient or family about palliative care out of concern that offering palliative care could be misconstrued as a suggestion to move away from curative or life-prolonging treatment. Additionally, patients and families are often unaware of the existence or availability of palliative services and may inaccurately assume that they are not eligible because these services are so often equated with hospice.<sup>143</sup>

Payment for healthcare services also creates barriers to the receipt of palliative care for patients with CVD and stroke. The Medicare Hospice Benefit provides payment for comprehensive palliative care services for those who are predictably dying, but the narrowness of this benefit precludes the vast majority of people who need comprehensive palliative care services from receiving them. Hospice is available to Medicare beneficiaries who have a life expectancy of  $\leq 6$  months if the illness runs its normal course.<sup>144</sup> For a beneficiary to elect hospice care, 2 physicians (the attending physician and a hospice physician) must certify that the beneficiary meets this criterion. Beneficiaries must "elect" the Medicare Hospice Benefit and agree to forgo Medicare coverage for curative treatment for their terminal illness. Under current policy, the first hospice benefit period is 90 days. If after 90 days the patient continues to remain eligible for hospice care (having a life expectancy of  $\leq 6$  months), the patient can be recertified for another 90 days and then recertified for an unlimited number of 60-day periods so long as he or she remains eligible for the benefit.<sup>145</sup>

Payment barriers are being addressed, however, with the Medicare program announcing on October 30, 2015, that physicians and other health professionals will be reimbursed for advance care planning discussions beginning January 1, 2016,<sup>146</sup> as well as the Centers for Medicare & Medicaid Services' concurrent hospice demonstration project called the Medicare Care Choices model.<sup>147</sup> Growing evidence of cost savings related to palliative care may obviate future financial barriers.<sup>148-151</sup>

## LEGISLATIVE ANALYSIS

Members of Congress have introduced a number of bills related to palliative care. These initiatives have included efforts to promote policy around advance care planning and advance directives, consumer and family caregiver education and support, professional education and workforce development, payment reform and quality measurement, and reform of the Medicare Hospice Benefit. The Coalition to Transform Advanced Care has compiled a comprehensive review of policy initiatives, summarized below.<sup>143</sup>

### Advance Care Planning/Advance Directives

In recent years, legislation encouraging advance care planning among aging populations has been championed by some in Congress. Such legislation has addressed a number of issues, including increasing patient awareness of advance care planning through a national public education campaign; establishing advance care directive toll-free information lines; including advance directives as part of an individual's medical record; providing grants to states to establish and operate state advance directive registries; providing coverage for advance care planning services in Medicaid and Medicare; and requiring that advance care planning materials be included in the *Medicare and You* handbook.<sup>152</sup>

### Consumer and Family Caregiver Education and Support

Legislation aimed at addressing the needs of the consumer and family caregiver in providing care for individuals in need of palliative care services has also been introduced. Policy options proposed in these bills include the creation of resource centers or national clearing houses of information and training materials, caregiver tax credits or stipends to offset the costs associated with being a caregiver, and state grants to assess and report on caregiver needs.

### Professional Education and Workforce Development

Several bills have been introduced to create a workforce and public health system that is better equipped to handle communication about and delivering palliative care services.<sup>153-154a</sup> Policy options put forth in these legislative efforts include developing advance care planning and palliative care curricula at medical schools and for continuing education, establishing hospice and palliative care academic career awards, providing specialized training for home health and nurse's aides in palliative care, and convening summits or developing expert panels to assess barriers to and develop solutions for care delivery integration and workforce development.

## Payment Reform and Quality Measurement

Legislation aimed at addressing payment for and quality of palliative care and hospice services has also been introduced. Policy options proposed in these bills include establishing demonstration projects to test advanced illness coordination; creating a national office of healthcare quality improvement or a national healthcare quality resource center; implementing a concurrent (palliative and curative) program for children; and directing the Medicare Payment Advisory Commission to examine payment for hospice care, taking into consideration the fact that the costs of providing hospice care are higher at the beginning and end of a hospice episode and lower during the middle of an episode.

### Expanding the Medicare Hospice Benefit

Other proposals have attempted to expand the Medicare Hospice Benefit to broader segments of the population or for longer durations of time. These policy options include making hospice a required Medicaid and Children's Health Insurance Program benefit<sup>154,154a</sup> and extending the hospice benefit to individuals with a life expectancy of 18 months from the current 6-month prognosis requirement.

## AHA/ASA GUIDING PRINCIPLES FOR PALLIATIVE CARE

Ensuring awareness of and access to palliative care aligns with the AHA/ASA mission and goals. To support this effort, the AHA/ASA convened a panel of experts to assist the association in developing a set of principles to guide its advocacy related to palliative care. These principles are summarized below.<sup>155</sup>

Recognizing that palliative care helps meet the priority needs of patients, better aligns patient care with preferences, supports clinical care best practices, and contributes to improved quality of care and outcomes for patients and families, the AHA/ASA supports a system of care that does the following:

- Provides patients with access to continuous, coordinated, comprehensive, high-quality palliative care provided simultaneously with specialist-level cardiovascular and stroke care
- Ensures well-prepared, empowered individuals and families
- Customizes care to reflect patient and family preferences and the unique situation of each individual
- Develops and supports a skilled, compassionate, and responsive healthcare workforce
- Embeds and actualizes continual structure and performance assessment against these principles.

## AHA/ASA POLICY RECOMMENDATIONS

On the basis of the guiding principles highlighted above, the following policy recommendations are provided as a means of ensuring patient-centered care in an environment that empowers the patient to receive care consistent with his or her values, goals, and preferences.

### Federal Agencies

Fully or partially funded federal programs such as Medicare and Medicaid offer a powerful lever to drive change within the healthcare system. Not only do these programs cover >100 million Americans, affecting the care of a large portion of the population, but actions taken by these programs are often replicated by private payers. In this way, the Centers for Medicare & Medicaid Services can use its role as a payer and developer of benefit packages to encourage the expanded, more comprehensive delivery of palliative care services. Private payers can replicate these models across their covered populations after they have been tested and evaluated in public programs or implement these changes as leaders in bringing quality palliative care services to their members.

**Recommendation 1:** Centers for Medicare & Medicaid Services should expand the situations in which it will reimburse for advance care planning discussions such as being part of the yearly wellness examination offered by Medicare or at the request of the patient at other engagement points with his/her healthcare provider.

**Recommendation 2:** Centers for Medicare & Medicaid Services should encourage that the decisions made in advance care planning discussions be documented in an individual's medical record.

Legislation that requires that palliative care options be documented in an individual's medical record has been introduced and obligates states to honor an advance directive or medical order regardless of where the document is presented. This is an important benefit for patients with advanced illness who are away from home when they suffer a health crisis.

**Recommendation 3:** Federal, state, and private insurance and healthcare delivery programs should provide financial incentives for healthcare providers to address the palliative care needs of their patients.

### State Agencies

State policy making is central to advancing the goals of palliative care because states can take steps to fill policy gaps even when there is an absence of federal policy in a particular area. For example, state Medicaid agencies could adopt codes and reimbursement for advance care planning discussions independently of federal action. Given the significant needs of patients and families with advanced CVD and stroke and their caregivers, there is a need to bridge the support for medical and social services

and support, facilitating patients remaining in community-based rather than institutional settings as disease progresses. Support for social and long-term care services is usually determined at the state level. State-level advocacy should thus target inclusion of palliative care and financing for integrated medical and social palliative care services as a critical component of long-term services and supports.

**Recommendation 4:** State Medicaid agencies should adopt codes and a reimbursement schedule for providers to engage in quality advance care planning discussions with their patients. This planning should include the provision of information about palliative options for those with stroke and CVD.

**Recommendation 5:** State Medicaid agencies should ensure that palliative care is integrated into long-term services and supports.

Several states have enacted palliative care legislation such as laws that establish palliative care advisory councils and those that mandate that patients with terminal illness are offered information about their palliative and end-of-life care options. In New York, relatively new palliative care laws require that information and counseling be offered to individuals who are terminally ill and that all individuals with advanced life-limiting conditions have access to palliative care.<sup>156,157</sup> Providers are required to develop written policies that ensure access to palliative care. New York also has a Palliative Care Education and Training Council, the members of which have expertise in pain management and palliative care. Oregon, Michigan, California, West Virginia, and Rhode Island have legislation in place that mandates pain management education and training for practitioners, sometimes as a prerequisite to licensure.<sup>158</sup> Other states have introduced such legislation but have not been successful in garnering enough support for it. Even when states enact innovative policies that aim to promote palliative care, implementation challenges still arise such as when these policies provide little or no support for the necessary education and training or they do not contain enforcement mechanisms.

**Recommendation 6:** State laws should require that hospitals, nursing homes, home care agencies, special needs assisted living residences, and enhanced assisted living residences provide access to information and counseling about options for palliative care appropriate to patients with advanced life-limiting conditions. These organizations must also facilitate access to appropriate palliative care consultation and services, including associated pain management consultation and services, consistent with the patient's needs and preferences.

As established by the Affordable Care Act (ACA), health plans offered in state health insurance marketplaces must include coverage for certain essential health benefits. Each state sets the benchmark for what is included in these plans, providing the opportunity for states to use this policy lever to encourage the inclusion of palliative care services as one of these required benefits.

**Recommendation 7:** States should require inclusion of palliative care in health plans offered through health insurance marketplaces.

State policies can also impede the advancement of palliative care as both a public health strategy and an interdisciplinary model of care. The World Health Organization public health strategy for palliative care includes 3 critical components: policy making, implementation of policy including policy addressing drug availability, and education and training.<sup>159</sup> The Pain and Policy Studies Group at the University of Wisconsin-Madison has systematically evaluated each state's policy agenda using metrics that target the goals of achieving balance in the regulation of controlled substances and availability of drugs to meet medical needs. The 2014 Report Card (calendar year 2013) presents evidence suggesting that states are making progress in the area of pain management, although not all states have achieved an A grade.<sup>160</sup>

State prescription monitoring programs also deserve mention. Almost all 50 states have prescription monitoring programs, and many have expanded them. For example, in New York, the Internet System for Tracking Over-Prescribing now mandates that every prescribing practitioner access a real-time registry to check a patient's history before prescribing certain controlled substances. Studies that have evaluated the effectiveness of prescription monitoring programs have yielded mixed results.<sup>161</sup> To optimize the effectiveness of state prescription monitoring programs and to ensure safe opioid use, providers should be trained in appropriate opioid prescribing.

**Recommendation 8:** States should evaluate the effectiveness of their prescription monitoring programs, with particular regard to the impact on the availability of essential medicines.

An overlooked area of state policy making is palliative care planning in the context of community resilience and disaster planning. The Institute of Medicine's 2012 report on crisis standards of care identifies palliative care as central to community planning for disasters.<sup>162</sup> The ethical underpinnings of palliative care—the duty to care and the duty not to abandon—undergird the allocation of resource decisions in situations of scarcity when not all individuals will receive the treatment they would get under normal circumstances. This is particularly important to consider because individuals with advanced CVD and stroke who likely have functional impairments are at higher risk in emergency and disaster situations.

**Recommendation 9:** State governments should allocate resources to community resilience and disaster planning that includes palliative care planning as a critical component.

## Payer-Provider Relationships

The ACA is driving innovations in care delivery toward both payer and provider accountability for patient outcomes

and cost efficiency (value). This recent attention to the link between better quality and lower cost has spurred an increase in mission alignment between payers and providers and resulted in payer-provider collaboration through initiatives such as shared data, coordinated services, joint public and professional educational activities, and benefit design. At the same time, the roles of payers and providers are converging, with payers increasingly providing direct healthcare services and providers increasingly operating health insurance plans. The benefits and drawbacks of this convergence and partnerships between payers and providers vary, but the phenomenon is growing rapidly. For palliative care, a model of care that has been unsupported by most current health system standards and payment practices, partnership between payers and providers is both opportune and necessary.

Although access to palliative care has grown considerably over the past decade (particularly in hospitals), for all those with serious illness—at all ages, in all care settings, and for all disease types and stages—to have access to the best-quality palliative care, payers and providers will need to work together. This is essential not only to provide payment mechanisms that make such care possible but also to identify patients at high risk for needing palliative care support, to develop standards and quality measures that drive quality and accountability, to incentivize and reward clinician training in palliative care knowledge and skills, and to help educate and engage the public about palliative care's benefits and advantages. The movement toward payer-provider partnerships offers a chance to advance the goal of providing high-quality palliative care for all people living with advanced CVD and stroke. However, as more of these partnerships come to fruition, it is important to keep in mind certain challenges that could affect their overall success.

Below are a few examples of the strategies that payers, providers, and other stakeholders can use to increase the likelihood that the partnerships will result in care that meets the needs of people with serious illness and their families across the trajectory of illness and the continuum of care. These recommendations assume that all healthcare providers are trained in primary palliative competencies and are knowledgeable about how to access specialty-level palliative care, as needed.

### Data Sharing

It is difficult to proactively identify patients with specialty-level palliative care needs. The lack of effective targeting strategies makes the problem of poor access to palliative care invisible and unquantifiable and prevents appropriate and timely referral. Many factors signal need for palliative care—for example, diagnoses, symptoms, prior healthcare use, functional and cognitive status, or clinical indicators such as frailty—but clinicians in the office or at the bedside need information technology and care management support to identify and then match services to the needs of each individual patient. Payers,

in contrast, have access to information on use and diagnoses and can use sophisticated analytics to predict palliative care needs. However, these analyses are also based on incomplete data in that they often do not include clinical data (eg, cognitive status or patient-reported outcomes) in the patient's medical record or clinical judgments (eg, evidence of family caregiver burden).

**Recommendation 10:** To identify patients who are likely to benefit from specialty-level palliative care services, payers and providers must collaborate by sharing and reviewing data. Once patients are proactively identified, their needs can be identified so that they can be referred to relevant services. For example, a payer can run analyses on claims data to produce an initial list of those who may benefit from palliative care. Then, the patient's clinician can provide clinical assessment of individual need for specialty-level palliative care.

Sharing of data is also crucial for ensuring that the palliative care services provided are meeting quality targets. One of the many benefits of palliative care is that patients are able to live safely and comfortably at home and experience fewer medical issues that require emergency department visits or hospitalizations. However, providers rarely have access to data on use (hospitalizations, emergency department visits) on the patients they serve. Health plans, on the other hand, assiduously monitor this information and can share this data with palliative providers so that providers can monitor the quality of their services.

**Recommendation 11:** Public policies should enhance and support information exchange and transparency between payers and providers while protecting the confidentiality of and preventing discrimination based on personal health information. Cumbersome policies that make information exchange between payers and providers difficult or poorly devised electronic health records policy (which can result in challenges such as lack of interoperability) can stifle these efforts. Public policy can also be proactive by incentivizing or mandating that certain data be shared between payers and providers. This would reduce reticence resulting from market pressures or economic concerns.

#### ***Aligning Reimbursement and Incentives to Encourage Quality***

Quality varies greatly across the palliative care services that patients are offered. Practice standards for the provision of palliative and end-of-life care for patients with advanced CVD and stroke are needed, along with quality performance standards to monitor care provided and to promote consistent palliative care provision. These standards should include interdisciplinary care practice and guidelines for the provision of advance care planning, including timing of discussions and care elements to be included in each related planning discussion. Quality metrics should reflect the specific challenges encountered and valued by seriously ill patients with advanced CVD and stroke.

The perverse incentives generated by the traditional fee-for-service payment system have been described fre-

quently and include the simple economic calculus that the more highly reimbursed services a provider delivers, the better he or she will be financially. Accordingly, providers may resist change in care processes that would benefit patients because of a fear of lost revenue. This is particularly true for the provision of and referrals to palliative care, care that often results in reduced acute care and specialist use.

**Recommendation 12:** Payers and providers must collaborate in an open and honest manner to identify perverse incentives and to redefine payment models to support care that is in the best interest of the patient. It is incumbent on providers to engage with payers to define care and payment models, to establish standards of quality, and to engage in the science of outcome measurement.

The ACA has done much to improve partnership in this area through its changes to the Medicare program, in particular the Medicare Shared Savings/Accountable Care Organization Program. Accountable Care Organizations are large groups of providers who agree to take on some level of financial risk in caring for their patient population through contracts with Medicare or other payers. When providers take on financial risk in caring for their population, they have aligned incentives to invest in care processes that reduce unnecessary expenditures. The propagation of Accountable Care Organization models is a starting point to restructure financial incentives for health care, but protections must be put in place to prevent inappropriate undertreatment of seriously ill and complex patient groups.

**Recommendation 13:** Accountable Care Organizations and other risk-bearing entities (including Medicare Advantage plans, managed Medicaid, and federally integrated dual-eligibility programs) should be held to clear standards to ensure that the care they deliver is of the highest quality. For example, the National Quality Forum, a public-private quality measure-endorsing body, works with the Centers for Medicare & Medicaid Services to link reliable and valid measures of quality to eligibility for payment.

The Center for Medicare and Medicaid Innovation, created by the ACA, has also spurred payer-provider partnerships through waivers of typical Medicare requirements, investment and infrastructure grants, and payment for new forms of care. One example of this is the Healthcare Innovation Awards, which, since 2012, have provided funding for almost 150 projects across the country, many of which include a payer-provider partnership component.

**Recommendation 14:** The Center for Medicare and Medicaid Innovation should make a point of selecting projects that test models of palliative care delivery to improve care for the sickest, most vulnerable beneficiaries.

#### ***Filling the Palliative Care Skills Gap and Improving Infrastructure***

Unfortunately, the healthcare workforce is not well equipped with the skills needed to support and care for the growing number of people (particularly older adults) living with serious, complex conditions in the United States and

globally. To provide evidence-based quality care, all clinicians who treat people with serious illness need to demonstrate competency and skills in communication, pain and symptom management, and health system coordination.

**Recommendation 15:** Healthcare systems and healthcare delivery organizations can support core palliative care skills acquisition by healthcare providers through such approaches as providing bonuses and payment for providers who demonstrate competency in these skills and mandating them as a requirement of employment or privileging.

**Recommendation 16:** Medicare can influence palliative care knowledge acquisition more powerfully than any other payer by reforming funding for graduate medical education to ensure that residents and fellows learn about communication and pain and symptom management, as well as other providers such as advanced practice nurses and physician assistants. Medicare can also work with the Accreditation Council for Graduate Medical Education to encourage standards for program accreditation that require reliable palliative care infrastructure and provider competency in palliative care clinical skills.

### Health Systems/Care Transitions

Health systems and individual healthcare settings, led by administrators or physician boards, can also play a role in changing the way that care and support are provided to patients and their families. These leaders can use hospital or system policy, processes, or initiatives to bring about better palliative care delivery within their own facility or system, as well as across systems and settings when transitions occur. The Center to Advance Palliative Care<sup>163</sup> is an important resource for those who are seeking to implement system-level change.

Patients who are hospitalized for the treatment of advanced CVD or in the aftermath of stroke and family caregivers for these patients have foreseeable needs during hospitalization in addition to medical treatment. Patients also need the assurance that they will be safe during care transitions, both within the hospital and from the hospital to different care settings such as rehabilitation hospitals, nursing homes, and home. The 3 domains—palliative care, planning and decision making, and safety during transitions—should be integrated into healthcare and hospital care systems from admission onward. These domains are particularly germane for young adults with CVD and stroke who are transitioning from pediatric to adult healthcare providers and systems.<sup>164</sup> System-level strategies to identify and trigger care for patients in need of primary and specialty-level palliative care obviate the need for accurate prognostication.

Improving palliative care for patients with serious cardiovascular conditions and in the aftermath of stroke includes broader professional access to generalist palliative care training and to better palliative care systems in communi-

ties. As long as palliative care expertise and resources are concentrated in hospitals (or in hospice programs), it will be difficult to ensure that palliative care needs will be met after a discharge to home care or other setting.

**Recommendation 17:** Healthcare providers and other clinicians who interface with patients with serious CVD and stroke should be familiar with palliative care resources within the hospital or other healthcare facility and in the communities served by the facility, as well as with gaps or problems in local access to palliative care services.

**Recommendation 18:** Care planning and decision-making processes, including discussions concerning goals of care, postdischarge needs, options, and resources, are patient directed and patient centered and are conducted in consultation with the patient's surrogate decision makers, family caregivers, and professionals responsible for the patient's care, including palliative care generalists and specialists as needed.

**Recommendation 19:** Hospital policy and practices should coordinate care planning, treatment decision making, and discharge planning processes for hospitalized patients to promote the development and modification of feasible care plans that reflect patients' palliative care needs and how these needs will be met during all transitions and in any new care settings.

**Recommendation 20:** Healthcare system processes should offer guidance in collaboration across institutions, for example, from an acute care hospital to a subacute care facility, to promote patient safety and well-being and to limit preventable rehospitalizations resulting from unmet palliative care needs or other problems with post-hospital care plans.

**Recommendation 21:** The early involvement of clinical social workers, clinical case managers, and other professionals with expert knowledge of postdischarge resources and payment mechanisms is crucial to the development of feasible post-hospitalization care plans. Discussions about care transitions and post-hospital care plans should include explicit attention to the capacities and limitations of family caregivers and to resolving conflicts between what a patient or family may prefer and what a patient's continuing care will require.

**Recommendation 22:** Transition processes for young adults aging out of a pediatric healthcare system should begin early and include partnerships with adult providers working in conjunction with pediatric providers to ensure seamless transitions. Payment mechanisms must also follow to enable both adult and pediatric providers to be reimbursed by care that may be accomplished concurrently for a period of time.

### Healthcare Provider Education in Palliative Care and Specialty Certification

Curricula in medical and nursing schools lack adequate attention to palliative care. Physicians, nurses, and other

clinicians tend to be educated in academic silos with little exposure to interprofessional teams and the necessary skill development to partner with patients and families for advance care planning and addressing physical, emotional, spiritual, and psychological needs.

The recent Institute of Medicine report *Dying in America* points out that to ensure the availability of palliative care to all people with advanced illness, including patients with CVD and stroke, all clinicians from all disciplines and specialties who take care of such patients “should be competent in basic palliative care, including communication skills, interprofessional collaboration, and symptom management.”<sup>6</sup> We agree with this principle and endorse the following recommendation of the Institute of Medicine report:

*Educational institutions, credentialing bodies, accrediting boards, state regulatory agencies, and healthcare delivery organizations should establish the appropriate training, certification, and/or licensure requirements to strengthen the palliative care knowledge and skills of all clinicians who care for individuals with advanced serious illness who are nearing the end of life.*<sup>6</sup>

Specialty certification in palliative care exists for physicians, social workers, nurses, advanced practice providers, and chaplains, and access to clinicians with this specialty-level palliative care certification is essential for patients with advanced CVD or stroke. Appendix 2 provides details about specialty certification for physicians, nurses, social workers, and chaplains.

The recommendations below, which are based on those in *Dying in America*, have been edited to reflect the focus of this statement on advanced CVD and stroke.

**Recommendation 23:** Educational institutions and professional societies should provide training in palliative care domains throughout the professional’s career.

**Recommendation 24:** Accrediting organizations such as the Accreditation Council for Graduate Medical Education should require palliative care education and clinical experience in programs for all specialties responsible for managing advanced CVD and stroke (including primary care clinicians).

**Recommendation 25:** Certifying bodies such as medical, nursing, social work, physician assistant, and chaplaincy specialty boards and health systems should require knowledge, skills, and competency in palliative care.

**Recommendation 26:** State regulatory agencies should include education and training in palliative care in licensure requirements for physicians, registered nurses, advanced practice nurses, physician assistants, social workers, and others who provide care to those with serious illness. Resources should be allocated to such education and training programs.

**Recommendation 27:** Entities that certify specialty-level healthcare providers should create pathways to certification that increase the number of healthcare professionals who pursue specialty-level palliative care training.

**Recommendation 28:** Entities such as healthcare delivery organizations, academic medical centers, and teaching hospitals, as well as community-based organizations that sponsor specialty-level training positions, should commit institutional resources to increasing the number of available training positions for specialty-level palliative care.

## CONCLUSIONS

Palliative care addresses the needs of people living with serious and chronic conditions, including CVDs and stroke. It seeks to improve QOL by preventing and relieving suffering and controlling symptoms. The healthcare team, patient, and family work together to develop a plan of care that reflects the values, preferences, and goals of the patient. In addition to relief of symptoms, important components of the palliative care plan are decisional, psychosocial, spiritual, and caregiver support. Evidence shows that when patients receive palliative care early in their illness trajectory, outcomes are better, including improved QOL, less depression, and longer survival. Additionally, the implementation of palliative care services is associated with a significant healthcare cost savings. However, gaps in knowledge must be addressed about optimal palliative care for patients with CVD, long-term outcomes associated with early and iterative use of palliative care in CVD, and effectiveness of primary palliative care for patients with CVD.<sup>109</sup>

Palliative care is an essential health benefit and central to high-quality overall care. In this policy statement on behalf of the AHA/ASA, we address the importance and benefits of integrating palliative care services in the care of seriously ill patients with CVD and stroke, and we provide policy recommendations based on the association’s guiding principles of comprehensive and high-quality palliative care, individualized care that reflects patient and family values and preferences, a skilled and compassionate workforce, and continual assessment and quality measurement. The healthcare community is experiencing a moment of enormous opportunity. The Medicare reforms included in the ACA have shaped a new trend in health care in which providers and payers have aligned incentives to work together to redefine care processes and payment models. The most important tasks now are to encourage continued and open dialog between payers and providers and to ensure that the new programs and initiatives meet the standards developed to provide the highest-quality care for people living with serious illness and their families.



## Appendix 1. American Heart Association/American Stroke Association Policy Recommendations for Palliative Care

Category	Recommendation
Federal agencies	1. CMS should expand the situations in which it will reimburse for advance care planning discussions, such as being part of the yearly wellness examination offered by Medicare or at the request of the patient at other engagement points with his/her healthcare provider.
	2. Medicare and Medicaid should encourage that the decisions made in advance care planning discussions be documented in an individual's medical record.
	3. All health insurance providers should provide financial incentives for healthcare providers to address the palliative care needs of their patients.
State agencies	4. State Medicaid agencies should adopt codes and a reimbursement schedule for providers to engage in quality advance care planning discussions with their patients. This planning should include the provision of information about palliative options for those with stroke and CVD.
	5. State Medicaid agencies should ensure that palliative care is integrated into long-term services and supports.
	6. State laws should require that hospitals, nursing homes, home care agencies, special needs assisted living residences, and enhanced assisted living residences provide access to information and counseling on options for palliative care appropriate to patients with advanced life-limiting conditions. These organizations must also facilitate access to appropriate palliative care consultation and services, including associated pain management consultation and services, consistent with the patient's needs and preferences.
	7. States should require inclusion of palliative care in health plans offered through health insurance marketplaces.
	8. States should evaluate the effectiveness of their prescription monitoring programs, with particular regard to the impact on the availability of essential medicines.
	9. State governments should allocate resources to community resilience and disaster planning that includes palliative care planning as a critical component.
Payer-provider relationships	10. To effectively identify those patients in need of specialty palliative care services, payers and providers must collaborate by sharing and reviewing data. Once patients are proactively identified, they can be stratified and referred to appropriate services.
	11. Public policies should enhance and support information exchange and transparency between payers and providers while protecting the confidentiality of and preventing discrimination based on personal health information. Cumbersome policies that make information exchange between payers and providers difficult or poorly devised electronic health records policy (which can result in challenges such as lack of interoperability) can stifle these efforts. Public policy can also be proactive by incentivizing or mandating that certain data be shared between payers and providers. This would reduce reticence resulting from market pressures or economic concerns.
	12. Payers and providers must collaborate in an open and honest manner to identify perverse incentives and to redefine payment models to support care that is in the best interest of the patient. It is incumbent on providers to engage with payers to define care and payment models, to establish standards of quality, and to engage in the science of outcome measurement.
	13. ACOs and other risk-bearing entities (including Medicare Advantage plans, managed Medicaid, and federally integrated dual-eligibility programs) should be held to clear standards to ensure that the care they deliver is of the highest quality. For example, the National Quality Forum, a public-private quality measure–endorsing body, works with the CMS to link reliable and valid measures of quality to eligibility for payment.
	14. The Center for Medicare and Medicaid Innovation should make a point to select projects that test models of palliative care delivery to improve care for the sickest, most vulnerable beneficiaries.
	15. Healthcare systems and healthcare delivery organizations can support core palliative care skills acquisition by healthcare providers through such approaches as providing bonuses and payment for providers who demonstrate competency in these skills and mandating them as a requirement of employment or privileging.
	16. Medicare can influence palliative care knowledge acquisition more powerfully than any other payer by reforming funding for graduate medical education to ensure residents and fellows learn about communication and pain and symptom management, as well as other providers such as advanced practice nurses and physician assistants. Medicare can also work with the ACGME to encourage standards for program accreditation that require reliable palliative care infrastructure and provider competency in palliative care clinical skills.

(Continued)

**Appendix 1. Continued**

Category	Recommendation
Health systems/ care transitions	17. Healthcare providers and other clinicians who interface with patients with serious CVD and stroke should be familiar with palliative care resources within the hospital or other healthcare facilities and in the communities served by the facility and with gaps or problems in local access to palliative care services.
	18. Care planning and decision-making processes, including discussions concerning goals of care, postdischarge needs, options, and resources, are patient directed and patient centered and are conducted in consultation with the patient's surrogate decision makers, family caregivers, and professionals responsible for the patient's care, including palliative care generalists and specialists as needed.
	19. Hospital policy and practices should coordinate care planning, treatment decision making, and discharge planning processes for hospitalized patients to promote the development and modification of feasible care plans that reflect patients' palliative care needs and how these needs will be met during all transitions and in any new care settings.
	20. Healthcare system processes should offer guidance in collaboration across institutions (eg, from an acute care hospital to a subacute care facility) to promote patient safety and well-being and to limit preventable rehospitalizations resulting from unmet palliative care needs or other problems with post-hospital care plans.
	21. The early involvement of clinical social workers and other professionals with expert knowledge of postdischarge resources and payment mechanisms is crucial to the development of feasible post-hospitalization care plans. Discussions about care transitions and post-hospital care plans should include explicit attention to the capacities and limitations of family caregivers and to resolving conflicts between what a patient or family may prefer and what a patient's continuing care will require.
	22. Transition processes for young adults aging out of a pediatric healthcare system should begin early and include partnerships with adult providers working in conjunction to smooth the process. Payment mechanisms must also follow to enable both adult and pediatric providers to be reimbursed for care that may be accomplished dually for a period of time.
	Healthcare provider education in palliative care and specialty certification
24. Accrediting organizations such as the ACGME should require palliative care education and clinical experience in programs for all specialties responsible for managing advanced CVD and stroke (including primary care clinicians).	
25. Certifying bodies such as medical, nursing, social work, and chaplaincy specialty boards and health systems should require knowledge, skills, and competency in palliative care.	
26. State regulatory agencies should include education and training in palliative care in licensure requirements for physicians, registered nurses, advanced practice nurses, physician assistants, social workers, and others who provide care to those with serious illness. Resources should be allocated to such education and training programs.	
27. Entities that certify specialty-level healthcare providers should create pathways to certification that increase the number of healthcare professionals who pursue specialty-level palliative care training.	
28. Entities such as healthcare delivery organizations, academic medical centers, and teaching hospitals, as well as community-based organizations that sponsor specialty-level training positions, should commit institutional resources to increasing the number of available training positions for specialty-level palliative care.	

ACGME indicates Accreditation Council for Graduate Medical Education; ACO, Accountable Care Organization; CMS, Centers for Medicare & Medicaid Services; and CVD, cardiovascular disease.

## APPENDIX 2: SPECIALTY PALLIATIVE CARE CERTIFICATION

### Physicians

The American Board of Medical Specialties formally recognizes specialties and subspecialties in allopathic medicine and confers specialty and subspecialty status. Although voluntary, this recognition is used by the government, healthcare systems, and insurers as evidence of high standards. Reflecting the roots of palliative medicine in many specialties, the American Board of Medical Specialties Hospice and Palliative Medicine (HPM) certification examination is offered by 10 specialty boards: the American Boards of Internal Medicine, Anesthesiology,

Family Medicine, Physical Medicine and Rehabilitation, Psychiatry and Neurology, Surgery, Pediatrics, Emergency Medicine, Radiology, and Obstetrics and Gynecology. The HPM certification examination is designed to evaluate the knowledge, diagnostic reasoning, and clinical judgment skills expected of the certified physician practicing in the broad domain of HPM. As of 2012, successful completion of an accredited HPM 12-month fellowship program is the only pathway to HPM American Board of Medical Specialties Board certification. Accreditation Council for Graduate Medical Education–accredited fellowship training must occur over a 12-month period with the elements outlined by the core curriculum in HPM. Fellowship training must occur in a minimum of 3 settings: inpatient hospital, long-term

care, and ambulatory care. Fellows in the 12-month period must complete the following minimum training sequence regardless of their primary specialty: a minimum of 4 months of inpatient palliative care consultation with experiences in inpatient hospice care, home hospice care, long-term care, and outpatient clinics. Fellows must complete a minimum of 25 home hospice visits and must have an outpatient clinic experience. Fellows must see a minimum of 100 new inpatient consultations and should follow up a minimum of 25 patients longitudinally across settings (eg, inpatient hospitalization, home, home hospice, inpatient hospice, and long-term care). Fellows must have training that exposes them to both adults and children and must be trained by an interdisciplinary team (eg, nurse, chaplains, social worker).<sup>165</sup>

### Nurses

The Hospice and Palliative Credentialing Center offers hospice and palliative certification to nurses and other members of the team. The Hospice and Palliative Credentialing Center offers 7 certification programs: Advanced Certified Hospice and Palliative Nurse, Certified Hospice and Palliative Nurse, Certified Hospice and Palliative Pediatric Nurse, Certified Hospice and Palliative Licensed Nurse, Certified Hospice and Palliative Nursing Assistant, Certified Hospice and Palliative Care Administrator, and Certified in Perinatal Loss Care. Both the Certified Hospice and Palliative Nurse and the Advanced Certified Hospice and Palliative Nurse examinations are accredited by the Accreditation Board for Specialty Nursing Certification. To take the Certified Hospice and Palliative Nurse or the Certified Hospice and Palliative Pediatric Nurse examination, the applicant must be currently licensed as a registered nurse or advanced practice registered nurse. Registered nurses must have hospice and palliative nursing or hospice and palliative pediatric nursing practice of 500 hours in the most recent 12 months or 1000 hours in the most recent 24 months before applying for the appropriate examination. To sit for the Advanced Practice Certified Hospice and Palliative Nurse examination, advanced practice registered nurses must hold a master's, postgraduate, or doctoral degree from an advanced practice nursing program that includes both didactic and clinical components and is accredited by the Commission on Collegiate Nursing Education or the Accreditation Commission for Education in Nursing. They should work as a clinical nurse specialist or nurse practitioner with 500 hours in the most recent 12 months or 1000 hours experience in the most recent 24 months in advanced practice hospice and palliative nursing. Certification is also available for licensed practical nurses and licensed vocational nurses.<sup>166</sup>

In addition to the certification examinations available through the Hospice and Palliative Credentialing Center, many universities offer graduate-level courses that teach

advanced knowledge in palliative care. This may be part of a specialty track within a master's or doctoral program, or a certificate may be awarded after completion of a program. The Hospice and Palliative Nurses Association, the nursing specialty organization for hospice and palliative nurses, offers numerous professional development products and services for nurses and professionals in the specialty.

### Social Workers

The Advanced Certified Hospice and Palliative Social Worker credential was created in 2008 with the support and partnership of the National Hospice and Palliative Care Organization at the Master of Social Work level. The Advanced Certified Hospice and Palliative Social Worker credential targets the development of specialized knowledge, skills, and capacities in palliative social work, especially for social workers in end-of-life care and those who practice social work in pain and symptom management. Eligibility requirements include a master's degree in social work from an accredited university, a current license to practice as a professional social worker,  $\geq 20$  continuing education units related specifically to hospice and palliative care, documentation of at least 2 years of supervised social work experience in hospice and palliative care, and adherence to National Association of Social Workers Code of Ethics and Standards for End of Life Care.<sup>167</sup> Masters-prepared social workers, however, are well equipped by virtue of their core social work training in family and social systems and principles of self-determination to practice palliative social work at the generalist level such as conducting basic pain assessments without specialized training or earning a certification.

### Chaplains

In the United States, professional healthcare chaplains are certified by 1 of 3 chaplaincy associations: the Association of Professional Chaplains (multifaith), the National Association of Catholic Chaplains, and Neshama: Association of Jewish Chaplains. These organizations share common competencies for chaplaincy certification. The requirements for hospice and palliative care specialty certification from the Association of Professional Chaplains include being a Board of Chaplaincy Certification Inc board-certified chaplain for at least 1 year; completion and documentation of a minimum of 3 years of clinical experience in hospice and palliative care; 3 recommendation letters; submission of a major essay that incorporates the theory and practice of chaplaincy care in hospice and palliative care ministry, along with a comprehensive case presentation; submission of an actual presentation and the accompanying script of no more than 20 slides; list of hospice and palliative care continuing education hours over the past 2 years (at least 15 hours each year); and the completion of a conference call interview.<sup>168</sup>

**FOOTNOTES**

The American Heart Association makes every effort to avoid any actual or potential conflicts of interest that may arise as a result of an outside relationship or a personal, professional, or business interest of a member of the writing panel. Specifically, all members of the writing group are required to complete and submit a Disclosure Questionnaire showing all such relationships that might be perceived as real or potential conflicts of interest.

This policy statement was approved by the American Heart Association Advocacy Coordinating Committee and the American Heart Association Executive Committee on March 28, 2016. A copy of the document is available at <http://professional.heart.org/statements> by using either “Search for Guidelines & Statements” or the “Browse by Topic” area. To purchase additional reprints, call 843-216-2533 or e-mail [kelle.ramsay@wolterskluwer.com](mailto:kelle.ramsay@wolterskluwer.com).

The American Heart Association requests that this document be cited as follows: Braun LT, Grady KL, Kutner JS, Adler E, Berlinger N, Boss R, Butler J, Enguidanos S, Friebert S, Gardner TJ, Higgins P, Holloway R, Konig M, Meier D, Morrissey MB, Quest

TE, Wiegand DL, Coombs-Lee B, Fitchett G, Gupta C, Roach WH Jr; on behalf of the American Heart Association Advocacy Coordinating Committee. Palliative care and cardiovascular disease and stroke: a policy statement from the American Heart Association/American Stroke Association. *Circulation*. 2016;134:XXX–XXX. DOI: 10.1161/CIR.0000000000000438.

Expert peer review of AHA Scientific Statements is conducted by the AHA Office of Science Operations. For more on AHA statements and guidelines development, visit <http://professional.heart.org/statements>. Select the “Guidelines & Statements” drop-down menu, then click “Publication Development.”

Permissions: Multiple copies, modification, alteration, enhancement, and/or distribution of this document are not permitted without the express permission of the American Heart Association. Instructions for obtaining permission are located at [http://www.heart.org/HEARTORG/General/Copyright-Permission-Guidelines\\_UCM\\_300404\\_Article.jsp](http://www.heart.org/HEARTORG/General/Copyright-Permission-Guidelines_UCM_300404_Article.jsp). A link to the “Copyright Permissions Request Form” appears on the right side of the page.

*Circulation* is available at <http://circ.ahajournals.org>

**DISCLOSURES**

**Writing Group Disclosures**

Writing Group Member	Employment	Research Grant	Other Research Support	Speakers' Bureau/Honoraria	Expert Witness	Ownership Interest	Consultant/Advisory Board	Other
Lynne T. Braun	Rush University College of Nursing	None	None	None	None	None	None	None
Kathleen L. Grady	Northwestern University	NIH† (principal investigator, TRANSIT NIH/NHLBI R34; principal investigator, SUSTAIN-IT NIH/NIA R01)	None	AHA*; HFSA*; ISHLT*	None	None	None	None
Jean S. Kutner	University of Colorado, School of Medicine	Research grants paid to the University of Colorado from the NIA†; NINR†	None	None	None	None	Medical editor, Informed Medical Decisions Foundation (via contract paid to the University of Colorado)†; National Advisory Committee, Paul Beeson Faculty Scholars in Aging Research Award*; Institute of Medicine Committee on Transforming End of Life Care* (2013–2014) (unpaid)	Organizational immediate past president, American Academy of Hospice and Palliative Medicine†
Eric Adler	University of California San Diego	None	None	None	None	None	Thoratec Corp*	None
Nancy Berlinger	The Hastings Center	None	None	None	None	None	None	None
Renee Boss	Johns Hopkins University	NICHHD† (principal investigator, Decision Making for Critically Ill Newborns)	None	None	None	None	None	None

(Continued)

**Writing Group Disclosures Continued**

Writing Group Member	Employment	Research Grant	Other Research Support	Speakers' Bureau/ Honoraria	Expert Witness	Ownership Interest	Consultant/ Advisory Board	Other
Javed Butler	Stony Brook University; American Heart Association	None	None	None	None	None	None	None
Barbara Coombs-Lee	Compassion & Choices	None	None	None	None	None	None	None
Susan Enguidanos	University of Southern California	NIH†; National Palliative Care Research Center*; Cambia Health Solutions*	None	None	None	None	Board member, California Coalition for Compassionate Care*	Salary: University of Southern California†
George Fitchett	Rush University Medical Center	None	None	None	None	None	None	None
Sarah Friebert	Akron Children's Hospital	CMMI HCIA Award, principal investigator*	None	None	None	None	Center to Advance Palliative Care*; NHPCO*	None
Timothy J. Gardner	Christiana Care Health System	None	None	None	None	None	None	None
Charu Gupta	University of California San Francisco	None	None	None	None	None	None	None
Phil Higgins	Psychotherapist and Palliative Care Consultant	None	None	None	None	None	None	None
Robert Holloway	University of Rochester	None	None	None	None	None	None	None
Madeleine Konig	American Heart Association	None	None	None	None	None	None	Salary: American Heart Association†
Diane Meier	Mount Sinai Medical Center; Hertzberg Palliative Care Institute	None	None	None	None	None	Sojourn's Scholars Advisory Board of the Cambia Health Foundation*	The Atlantic Philanthropies†; The Berkman Charitable Trust†; The Brookdale Foundation†; Cambia Health Foundation†; Cameron and Hayden Lord Foundation†; Gary and Mary West Foundation†; Gordon and Betty Moore Foundation†; The John A. Hartford Foundation†; The Leslie and Roslyn Goldstein Foundation†; Milbank Foundation†; The Olive Branch Fund†; The Pat and Jay Baker Foundation†; Stavros Niarchos Foundation†; The Y. C. Ho/Helen & Michael Chiang Foundation†; West Health Institute†

(Continued)

**POLICY STATEMENTS**

## Writing Group Disclosures Continued

Writing Group Member	Employment	Research Grant	Other Research Support	Speakers' Bureau/ Honoraria	Expert Witness	Ownership Interest	Consultant/ Advisory Board	Other
Mary Beth Morrissey	Fordham University; Collaborative for Palliative Care	NIA* (principal investigator, Pilot Award Grant from Translational Institute on Pain in Later Life (5P30AG022845-10); Weill Cornell Medical College (2013–2014)*	None	None	None	None	None	None
Tammie E. Quest	Emory University School of Medicine; Department of Veterans Affairs, Atlanta VAMC	None	None	None	None	None	None	None
William H. Roach, Jr	Retired partner, McDermott Will & Emery LLP	None	None	None	None	None	None	None
Debra L. Wiegand	University of Maryland School of Nursing	NIH/NINR†	None	None	None	None	None	None

This table represents the relationships of writing group members that may be perceived as actual or reasonably perceived conflicts of interest as reported on the Disclosure Questionnaire, which all members of the writing group are required to complete and submit. A relationship is considered to be “significant” if (a) the person receives \$10 000 or more during any 12-month period, or 5% or more of the person’s gross income; or (b) the person owns 5% or more of the voting stock or share of the entity, or owns \$10 000 or more of the fair market value of the entity. A relationship is considered to be “modest” if it is less than “significant” under the preceding definition.

\*Modest.

†Significant.

## Reviewer Disclosures

Reviewer	Employment	Research Grant	Other Research Support	Speakers' Bureau/ Honoraria	Expert Witness	Ownership Interest	Consultant/ Advisory Board	Other
Larry A. Allen	University of Colorado School of Medicine	PCORI†; NIH NHLBI (K23 HL105896)†	None	None	None	None	Novartis†	None
Claire J. Creutzfeldt	Harborview Medical Center	Cambia Health Foundation* (Palliative Care Leadership Award)	None	None	None	None	None	None
Barbara J. Lutz	University of North Carolina-Wilmington	PCORI* (consultant on a PCORI grant comparing outcomes for stroke patients receiving care from an inpatient rehab hospital and subacute care); PCORI† (coinvestigator on a PCORI-funded study related to stroke)	None	None	None	None	None	None
Kristen G. Schaefer	Brigham and Women's Hospital	None	None	None	None	None	None	None

This table represents the relationships of reviewers that may be perceived as actual or reasonably perceived conflicts of interest as reported on the Disclosure Questionnaire, which all reviewers are required to complete and submit. A relationship is considered to be “significant” if (a) the person receives \$10 000 or more during any 12-month period, or 5% or more of the person’s gross income; or (b) the person owns 5% or more of the voting stock or share of the entity, or owns \$10 000 or more of the fair market value of the entity. A relationship is considered to be “modest” if it is less than “significant” under the preceding definition.

\*Modest.

†Significant.

## REFERENCES

- Holloway RG, Arnold RM, Creutzfeldt CJ, Lewis EF, Lutz BJ, McCann RM, Rabinstein AA, Saposnik G, Sheth KN, Zahuranec DB, Zipfel GJ, Zorowitz RD; on behalf of the American Heart Association Stroke Council, Council on Cardiovascular and Stroke Nursing, and Council on Clinical Cardiology. Palliative and end-of-life care in stroke: a statement for healthcare professionals from the American Heart Association/American Stroke Association. *Stroke*. 2014;45:1887–1916. doi: 10.1161/STR.000000000000015.
- Allen LA, Stevenson LW, Grady KL, Goldstein NE, Matlock DD, Arnold RM, Cook NR, Felker GM, Francis GS, Hauptman PJ, Havranek EP, Krumholz HM, Mancini D, Riegel B, Spertus JA; on behalf of the American Heart Association Council on Quality of Care and Outcomes Research, Council on Cardiovascular Nursing, Council on Clinical Cardiology, Council on Cardiovascular Radiology and Intervention, and Council on Cardiovascular Surgery and Anesthesia. Decision making in advanced heart failure: a scientific statement from the American Heart Association. *Circulation*. 2012;125:1928–1952. doi: 10.1161/CIR.0b013e31824f2173.
- Dahlin C; National Consensus Project for Quality Palliative Care Task Force. *Clinical Practice Guidelines for Quality Palliative Care*. Pittsburgh, PA: National Consensus Project; 2013.
- World Health Organization. Global atlas of palliative care at the end of life. 2014. [http://www.who.int/nmh/Global\\_Atlas\\_of\\_Palliative\\_Care.pdf](http://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf). Accessed January 6, 2016.
- Quill TE, Abernethy AP. Generalist plus specialist palliative care: creating a more sustainable model. *N Engl J Med*. 2013;368:1173–1175. doi: 10.1056/NEJMp1215620.
- Institute of Medicine. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. Washington, DC: National Academies Press; 2015.
- Mozaffarian D, Benjamin EJ, Go AS, Arnett DK, Blaha MJ, Cushman M, de Ferranti S, Després JP, Fullerton HJ, Howard VH, Huffman MD, Judd SE, Kissela BM, Lackland DT, Lichtman JH, Lisabeth LD, Liu S, Mackey RH, Matchar DB, McGuire DK, Mohler ER 3rd, Moy CS, Muntner P, Mussolino ME, Nasir K, Neumar RW, Nichol G, Palaniappan L, Pandey DK, Reeves MJ, Rodriguez CJ, Sorlie PD, Stein J, Towfighi A, Turan TN, Virani SS, Willey JZ, Woo D, Yeh RW, Turner MB; on behalf of the American Heart Association Statistics Committee and Stroke Statistics Subcommittee. Heart disease and stroke statistics 2015—update: a report from the American Heart Association [published correction appears in *Circulation*. 2015;131:e535]. *Circulation*. 2015;131:e29–e322. doi: 10.1161/CIR.0000000000000152.
- Fang JC, Ewald GA, Allen LA, Butler J, Westlake Canary CA, Colvin-Adams M, Dickinson MG, Levy P, Stough WG, Sweitzer NK, Teerlink JR, Whellan DJ, Albert NM, Krishnamani R, Rich MW, Walsh MN, Bonnell MR, Carson PE, Chan MC, Dries DL, Hernandez AF, Hershberger RE, Katz SD, Moore S, Rodgers JE, Rogers JG, Vest AR, Givertz MM; Heart Failure Society of America Guidelines Committee. Advanced (stage D) heart failure: a statement from the Heart Failure Society of America Guidelines Committee. *J Card Fail*. 2015;21:519–534. doi: 10.1016/j.cardfail.2015.04.013.
- Ammar KA, Jacobsen SJ, Mahoney DW, Kors JA, Redfield MM, Burnett JC Jr, Rodeheffer RJ. Prevalence and prognostic significance of heart failure stages: application of the American College of Cardiology/American Heart Association heart failure staging criteria in the community. *Circulation*. 2007;115:1563–1570. doi: 10.1161/CIRCULATIONAHA.106.666818.
- Yancy CW, Jessup M, Bozkurt B, Butler J, Casey DE Jr, Drazner MH, Fonarow GC, Geraci SA, Horwich T, Januzzi JL, Johnson MR, Kasper EK, Levy WC, Masoudi FA, McBride PE, McMurray JJV, Mitchell JE, Peterson PN, Riegel B, Sam F, Stevenson LW, Tang WHW, Tsai EJ, Wilkoff BL. 2013 ACCF/AHA guideline for the management of heart failure: a report of the American College of Cardiology Foundation/American Heart Association Task Force on Practice Guidelines. *Circulation*. 2013;128:e240–e327. doi: 10.1161/CIR.0b013e31829e8776.
- Aaronson KD, Schwartz JS, Chen TM, Wong KL, Goin JE, Mancini DM. Development and prospective validation of a clinical index to predict survival in ambulatory patients referred for cardiac transplant evaluation. *Circulation*. 1997;95:2660–2667. doi: 10.1161/01.CIR.95.12.2660.
- Hsieh E, Gorodeski EZ, Blackstone EH, Ishwaran H, Lauer MS. Identifying important risk factors for survival in patient with systolic heart failure using random survival forests. *Circ Cardiovasc Qual Outcomes*. 2011;4:39–45. doi: 10.1161/CIRCOUTCOMES.110.939371.
- Levy WC, Mozaffarian D, Linker DT, Sutradhar SC, Anker SD, Cropp AB, Anand I, Maggioni A, Burton P, Sullivan MD, Pitt B, Poole-Wilson PA, Mann DL, Packer M. The Seattle Heart Failure Model: prediction of survival in heart failure. *Circulation*. 2006;113:1424–1433. doi: 10.1161/CIRCULATIONAHA.105.584102.
- Metra M, Ponikowski P, Dickstein K, McMurray JJ, Gavazzi A, Bergh CH, Fraser AG, Jaarsma T, Pitsis A, Mohacs P, Böhm M, Anker S, Dargie H, Brutsaert D, Komajda M; Heart Failure Association of the European Society of Cardiology. Advanced chronic heart failure: a position statement from the Study Group on Advanced Heart Failure of the Heart Failure Association of the European Society of Cardiology. *Eur J Heart Fail*. 2007;9:684–694. doi: 10.1016/j.ejheart.2007.04.003.
- Stevenson LW, Pagani FD, Young JB, Jessup M, Miller L, Kormos RL, Naftel DC, Ulisney K, Desvigne-Nickens P, Kirklin JK. INTERMACS profiles of advanced heart failure: the current picture. *J Heart Lung Transplant*. 2009;28:535–541. doi: 10.1016/j.healun.2009.02.015.
- O'Connor CM, Hasselblad V, Mehta RH, Tassisa G, Califf RM, Fuzat M, Rogers JG, Leier CV, Stevenson LW. Triage after hospitalization with advanced heart failure: the ESCAPE (Evaluation Study of Congestive Heart Failure and Pulmonary Artery Catheterization Effectiveness) risk model and discharge score. *J Am Coll Cardiol*. 2010;55:872–878. doi: 10.1016/j.jacc.2009.08.083.
- Lee DS, Austin PC, Rouleau JL, Liu PP, Naimark D, Tu JV. Predicting mortality among patients hospitalized for heart failure: derivation and validation of a clinical model. *JAMA*. 2003;290:2581–2587. doi: 10.1001/jama.290.19.2581.
- Mancini DM, Eisen H, Kussmaul W, Mull R, Edmunds LH Jr, Wilson JR. Value of peak exercise oxygen consumption for optimal timing of cardiac transplantation in ambulatory patients with heart failure. *Circulation*. 1991;83:778–786. doi: 10.1161/01.CIR.83.3.778.
- Zuccalà G, Pedone C, Cesari M, Onder G, Pahor M, Marzetti E, Lo Monaco MR, Cocchi A, Carbonin P, Bernabei R. The effects of cognitive impairment on mortality among hospitalized patients with heart failure. *Am J Med*. 2003;115:97–103. doi: [http://dx.doi.org/10.1016/S0002-9343\(03\)00264-X](http://dx.doi.org/10.1016/S0002-9343(03)00264-X).
- Hersh AM, Masoudi FA, Allen LA. Postdischarge environment following heart failure hospitalization: expanding the view of hospital readmission. *J Am Heart Assoc*. 2013;2:e000116. doi: 10.1161/JAHA.113.000116.
- Rose EA, Gelijns AC, Moskowitz AJ, Heitjan DF, Stevenson LW, Dembitsky W, Long JW, Ascheim DD, Tierney AR, Levitan RG, Watson JT, Meier P, Ronan NS, Shapiro PA, Lazar RM, Miller LW, Gupta L, Frazier OH, Desvigne-Nickens P, Oz MC, Poirier VL; Randomized Evaluation of Mechanical Assistance for the Treatment of Congestive Heart Failure (REMATCH) Study Group. Long-term use of a left ventricular assist device for end-stage heart failure. *N Engl J Med*. 2001;345:1435–1443. doi: 10.1056/NEJMoa012175.
- Rogers JG, Butler J, Lansman SL, Gass A, Portner PM, Pasque MK, Pierson RN 3rd; INTrEPID Investigators. Chronic mechanical circulatory support for inotrope-dependent heart failure patients who are not transplant candidates: results of the INTrEPID Trial. *J Am Coll Cardiol*. 2007;50:741–747. doi: 10.1016/j.jacc.2007.03.063.

23. Hershberger RE, Nauman D, Walker TL, Dutton D, Burgess D. Care processes and clinical outcomes of continuous outpatient support with inotropes (COSI) in patients with refractory end-stage heart failure. *J Card Fail*. 2003;9:180–187. doi: 10.1054/jcaf.2003.24.
24. Estep JD, Starling RC, Horstmanshof DA, Milano CA, Selzman CH, Shah KB, Loebe M, Moazami N, Long JW, Stehlik J, Kasirajan V, Haas DC, O'Connell JB, Boyle AJ, Farrar DJ, Rogers JG; ROADMAP Study Investigators. Risk assessment and comparative effectiveness of left ventricular assist device and medical management in ambulatory heart failure patients: results from the ROADMAP Study. *J Am Coll Cardiol*. 2015;66:1747–1761. doi: 10.1016/j.jacc.2015.07.075.
25. Allen LA, Yager JE, Funk MJ, Levy WC, Tulsy JA, Bowers MT, Dodson GC, O'Connor CM, Felker GM. Discordance between patient-predicted and model-predicted life expectancy among ambulatory patients with heart failure. *JAMA*. 2008;299:2533–2542. doi: 10.1001/jama.299.21.2533.
26. Hallas CN, Wray J, Andreou P, Banner NR. Depression and perceptions about heart failure predict quality of life in patients with advanced heart failure. *Heart Lung*. 2011;40:111–121. doi: 10.1016/j.hrtlng.2009.12.008.
27. Zambroski CH, Moser DK, Bhat G, Ziegler C. Impact of symptom prevalence and symptom burden on quality of life in patients with heart failure. *Eur J Cardiovasc Nurs*. 2005;4:198–206. doi: 10.1016/j.ejcnurse.2005.03.010.
28. Grady KL, Jalowiec A, White-Williams C, Pifarre R, Kirklín JK, Bourge RC, Costanzo MR. Predictors of quality of life in patients with advanced heart failure awaiting transplantation. *J Heart Lung Transplant*. 1995;14(pt 1):2–10.
29. Muirhead J, Meyerowitz BE, Leedham B, Eastburn TE, Merrill WH, Frist WH. Quality of life and coping in patients awaiting heart transplantation. *J Heart Lung Transplant*. 1992;11(pt 1):265–271.
30. Dracup K, Walden JA, Stevenson LW, Brecht ML. Quality of life in patients with advanced heart failure. *J Heart Lung Transplant*. 1992;11(pt 1):273–279.
31. Rutledge T, Reis VA, Linke SE, Greenberg BH, Mills PJ. Depression in heart failure: a meta-analytic review of prevalence, intervention effects, and associations with clinical outcomes. *J Am Coll Cardiol*. 2006;48:1527–1537. doi: 10.1016/j.jacc.2006.06.055.
32. Moraska AR, Chamberlain AM, Shah ND, Vickers KS, Rummans TA, Dunlay SM, Spertus JA, Weston SA, McNallan SM, Redfield MM, Roger VL. Depression, healthcare utilization, and death in heart failure: a community study. *Circ Heart Fail*. 2013;6:387–394. doi: 10.1161/CIRCHEARTFAILURE.112.000118.
33. Wu JR, Lennie TA, Dekker RL, Biddle MJ, Moser DK. Medication adherence, depressive symptoms, and cardiac event-free survival in patients with heart failure. *J Card Fail*. 2013;19:317–324. doi: 10.1016/j.cardfail.2013.03.010.
34. Medoff-Cooper B, Naim M, Torowicz D, Mott A. Feeding, growth, and nutrition in children with congenitally malformed hearts. *Cardiol Young*. 2010;20(suppl 3):149–153. doi: 10.1017/S1047951110001228.
35. Blume ED, Balkin EM, Aiyagari R, Ziniel S, Beke DM, Thiagarajan R, Taylor L, Kulik T, Pituch K, Wolfe J. Parental perspectives on suffering and quality of life at end-of-life in children with advanced heart disease: an exploratory study. *Pediatr Crit Care Med*. 2014;15:336–342. doi: 10.1097/PCC.0000000000000072.
36. Adler ED, Goldfinger JZ, Kalman J, Park ME, Meier DE. Palliative care in the treatment of advanced heart failure. *Circulation*. 2009;120:2597–2606. doi: 10.1161/CIRCULATIONAHA.109.869123.
37. Brännström M, Ekman I, Boman K, Strandberg G. Being a close relative of a person with severe, chronic heart failure in palliative advanced home care: a comfort but also a strain. *Scand J Caring Sci*. 2007;21:338–344. doi: 10.1111/j.1471-6712.2007.00485.x.
38. Malik FA, Gysels M, Higginson JI. Living with breathlessness: a survey of caregivers of breathless patients with lung cancer or heart failure. *Palliat Med*. 2013;27:647–656. doi: 10.1177/0269216313488812.
39. Carlsson ME. Sleep disturbance in relatives of palliative patients cared for at home. *Palliat Support Care*. 2012;10:165–170. doi: 10.1017/S1478951511000836.
40. Gysels MH, Higginson JI. Caring for a person in advanced illness and suffering from breathlessness at home: threats and resources. *Palliat Support Care*. 2009;7:153–162. doi: 10.1017/S1478951509000200.
41. Lund LH, Edwards LB, Kucheryavaya AY, Dipchand AI, Benden C, Christie JD, Dobbels F, Kirk R, Rahmel AO, Yusef RD, Stehlik J; International Society for Heart and Lung Transplantation. The Registry of the International Society for Heart and Lung Transplantation: Thirtieth Official Adult Heart Transplant Report—2013; focus theme: age. *J Heart Lung Transplant*. 2013;32:951–964. doi: 10.1016/j.healun.2013.08.006.
42. Kirklín JK, Naftel DC, Kormos RL, Stevenson LW, Pagani FD, Miller MA, Ullisney KL, Baldwin JT, Young JB. Third INTERMACS Annual Report: the evolution of destination therapy in the United States. *J Heart Lung Transplant*. 2011;30:115–123. doi: 10.1016/j.healun.2010.12.001.
43. Colvin-Adams M, Smithy JM, Heubner BM, Skeans MA, Edwards LB, Waller C, Schnitzler MA, Snyder JJ, Israni AK, Kasiske BL. OPTN/SRTR 2012 Annual Data Report: heart. *Am J Transplant*. 2014;14(suppl 1):113–138. doi: 10.1111/ajt.12583.
44. Dipchand AI, Edwards LB, Kucheryavaya AY, Benden C, Dobbels F, Levvey BJ, Lund LH, Meiser B, Yusef RD, Stehlik J; International Society of Heart and Lung Transplantation. The registry of the International Society for Heart and Lung Transplantation: seventeenth official pediatric heart transplantation report—2014; focus theme: retransplantation. *J Heart Lung Transplant*. 2014;33:985–995. doi: 10.1016/j.healun.2014.08.002.
45. Martinelli V, Fusar-Poli P, Emanuele E, Klersy C, Campana C, Barale F, Viganò M, Politi P. Getting old with a new heart: impact of age on depression and quality of life in long-term heart transplant recipients. *J Heart Lung Transplant*. 2007;26:544–548. doi: 10.1016/j.healun.2007.01.023.
46. Grady KL, Naftel DC, Kobashigawa J, Chait J, Young JB, Pelegri D, Czern J, Heroux A, Higgins R, Rybarczyk B, McLeod M, White-Williams C, Kirklín JK. Patterns and predictors of quality of life at 5 to 10 years after heart transplantation. *J Heart Lung Transplant*. 2007;26:535–543. doi: 10.1016/j.healun.2007.01.042.
47. Grady KL, Jalowiec A, White-Williams C. Improvement in quality of life in patients with heart failure who undergo transplantation. *J Heart Lung Transplant*. 1996;15:749–757.
48. Uzark K, Griffin L, Rodriguez R, Zamberlan M, Murphy P, Nasman C, Dupuis J, Rodgers S, Limbers CA, Varni JW. Quality of life in pediatric heart transplant recipients: a comparison with children with and without heart disease. *J Heart Lung Transplant*. 2012;31:571–578. doi: 10.1016/j.healun.2012.01.867.
49. Pollock-BarZiv SM, Anthony SJ, Niedra R, Dipchand AI, West LJ. Quality of life and function following cardiac transplantation in adolescents. *Transplant Proc*. 2003;35:2468–2470. doi: http://dx.doi.org/10.1016/j.transproceed.2003.08.028.
50. Parent JJ, Sterrett L, Caldwell R, Darragh R, Schamberger M, Murphy D, Ebenroth E. Quality of life following paediatric heart transplant: are age and activity level factors? *Cardiol Young*. 2015;25:476–480. doi: 10.1017/S1047951114000134.
51. Petroski RA, Grady KL, Rodgers S, Backer CL, Kulikowska A, Canter C, Pahl E. Quality of life in adult survivors greater than 10 years after pediatric heart transplantation. *J Heart Lung Transplant*. 2009;28:661–666. doi: 10.1016/j.healun.2009.04.004.
52. Hollander SA, Chen S, Luikart H, Burge M, Hollander AM, Rosenthal DN, Maeda K, Hunt SA, Bernstein D. Quality of life and metrics of achievement in long-term adult survivors of pediatric heart



- transplant. *Pediatr Transplant*. 2015;19:76–81. doi: 10.1111/ptr.12384.
53. Myaskovsky L, Posluszny DM, Schulz R, DiMartini AF, Switzer GE, DeVito Dabbs A, McNulty ML, Kormos RL, Toyoda Y, Dew MA. Predictors and outcomes of health-related quality of life in caregivers of cardiothoracic transplant recipients. *Am J Transplant*. 2012;12:3387–3397. doi: 10.1111/j.1600-6143.2012.04243.x.
  54. Goetzinger AM, Blumenthal JA, O'Hayer CV, Babyak MA, Hoffman BM, Ong L, Davis RD, Smith SR, Rogers JG, Milano CA, Smith AD, Kuo PC, Palmer SM. Stress and coping in caregivers of patients awaiting solid organ transplantation. *Clin Transplant*. 2012;26:97–104. doi: 10.1111/j.1399-0012.2011.01431.x.
  55. Rodrigue JR, MacNaughton K, Hoffmann RG 3rd, Graham-Pole J, Andres JM, Novak DA, Fennell RS. Transplantation in children: a longitudinal assessment of mothers' stress, coping, and perceptions of family functioning. *Psychosomatics*. 1997;38:478–486. doi: 10.1016/S0033-3182(97)71425-7.
  56. Kirklin JK, Naftel DC, Pagani FD, Kormos RL, Stevenson LW, Blume ED, Miller MA, Baldwin JT, Young JB. Sixth INTERMACS annual report: a 10,000-patient database [published correction appears in *J Heart Lung Transplant*. 2015;34:1356]. *J Heart Lung Transplant*. 2014;33:555–564. doi: 10.1016/j.healun.2014.04.010.
  57. Holman WL, Kormos RL, Naftel DC, Miller MA, Pagani FD, Blume E, Cleeton T, Koenig SC, Edwards L, Kirklin JK. Predictors of death and transplant in patients with a mechanical circulatory support device: a multi-institutional study. *J Heart Lung Transplant*. 2009;28:44–50. doi: 10.1016/j.healun.2008.10.011.
  58. Boyle AJ, Ascheim DD, Russo MJ, Kormos RL, John R, Naka Y, Gelijns AC, Hong KN, Teuteberg JJ. Clinical outcomes for continuous-flow left ventricular assist device patients stratified by pre-operative INTERMACS classification. *J Heart Lung Transplant*. 2011;30:402–407. doi: 10.1016/j.healun.2010.10.016.
  59. Mansfield RT, Lin KY, Zaoutis T, Mott AR, Mohamad Z, Luan X, Kaufman BD, Ravishanker C, Gaynor JW, Shaddy RE, Rossano JW. The use of pediatric ventricular assist devices in children's hospitals from 2000 to 2010: morbidity, mortality, and hospital charges. *Pediatr Crit Care Med*. 2015;16:522–528. doi: 10.1097/PCC.0000000000000401.
  60. Adachi I, Khan MS, Guzmán-Pruneda FA, Fraser CD 3rd, Mery CM, Denfield SW, Dreyer WJ, Morales DL, McKenzie ED, Heinle JS, Fraser CD Jr. Evolution and impact of ventricular assist device program on children awaiting heart transplantation. *Ann Thorac Surg*. 2015;99:635–640. doi: 10.1016/j.athoracsur.2014.10.010.
  61. Davies RR, Haldeman S, McCulloch MA, Pizarro C. Ventricular assist devices as a bridge-to-transplant improve early post-transplant outcomes in children. *J Heart Lung Transplant*. 2014;33:704–712. doi: 10.1016/j.healun.2014.02.010.
  62. Hasin T, Marmor Y, Kremers W, Topilsky Y, Severson CJ, Schirger JA, Boilson BA, Clavell AL, Rodeheffer RJ, Frantz RP, Edwards BS, Pereira NL, Stulak JM, Joyce L, Daly R, Park SJ, Kushwaha SS. Readmissions after implantation of axial flow left ventricular assist device. *J Am Coll Cardiol*. 2013;61:153–163. doi: 10.1016/j.jacc.2012.09.041.
  63. Forest SJ, Bello R, Friedmann P, Casazza D, Nucci C, Shin JJ, D'Alessandro D, Stevens G, Goldstein DJ. Readmissions after ventricular assist device: etiologies, patterns, and days out of hospital. *Ann Thorac Surg*. 2013;95:1276–1281. doi: 10.1016/j.athoracsur.2012.12.039.
  64. Smedira NG, Hoercher KJ, Lima B, Mountis MM, Starling RC, Thuita L, Schmuhl DM, Blackstone EH. Unplanned hospital readmissions after HeartMate II implantation: frequency, risk factors, and impact on resource use and survival. *JACC Heart Fail*. 2013;1:31–39. doi: 10.1016/j.jchf.2012.11.001.
  65. Grady KL, Naftel D, Stevenson L, Dew MA, Weidner G, Pagani FD, Kirklin JK, Myers S, Baldwin T, Young J. Overall quality of life improves to similar levels after mechanical circulatory support regardless of severity of heart failure before implantation. *J Heart Lung Transplant*. 2014;33:412–421. doi: 10.1016/j.healun.2013.10.017.
  66. Maciver J, Ross HJ. Quality of life and left ventricular assist device support. *Circulation*. 2012;126:866–874. doi: 10.1161/CIRCULATIONAHA.111.040279.
  67. Petrucci RJ, Wright S, Naka Y, Idrissi KA, Russell SD, Dordunoo D, Jaski B, Chillcott S, Feldman D, Yanssens T, Heatley G, Koundakjian L, Farrar DJ, Aaronson KD; HeartMate II Clinical Investigators. Neurocognitive assessments in advanced heart failure patients receiving continuous-flow left ventricular assist devices. *J Heart Lung Transplant*. 2009;28:542–549. doi: 10.1016/j.healun.2009.02.007.
  68. Casida J. The lived experience of spouses of patients with a left ventricular assist device before heart transplantation. *Am J Crit Care*. 2005;14:145–151.
  69. Ozbaran B, Kose S, Yagdi T, Engin C, Erermis S, Yazici KU, Noyan A, Ozbaran M. Depression and anxiety levels of the mothers of children and adolescents with left ventricular assist devices. *Pediatr Transplant*. 2012;16:766–770. doi: 10.1111/j.1399-3046.2012.01755.x.
  70. Kirkpatrick JN, Kellom K, Hull SC, Henderson R, Singh J, Coyle LA, Mountis M, Shore ED, Petrucci R, Cronholm PF, Barg FK. Caregivers and left ventricular assist devices as a destination, not a journey. *J Card Fail*. 2015;21:806–815. doi: 10.1016/j.cardfail.2015.05.016.
  71. Brouwers C, Caliskan K, de Jonge N, Theuns DA, Constantinescu A, Young QR, Cannon C, Denollet J, Pedersen SS. A comparison of the health status and psychological distress of partners of patients with a left ventricular assist device versus an implantable cardioverter defibrillator: a preliminary study. *Heart Lung*. 2015;44:27–32. doi: 10.1016/j.hrtlng.2014.10.007.
  72. Creutzfeldt CJ, Longstreth WT, Holloway RG. Predicting decline and survival in severe acute brain injury: the fourth trajectory. *BMJ*. 2015;351:h3904. doi: http://dx.doi.org/10.1136/bmj.h3904.
  73. Geurts M, Macleod MR, van Thiel GJ, van Gijn J, Kappelle LJ, van der Worp HB. End-of-life decisions in patients with severe acute brain injury. *Lancet Neurol*. 2014;13:515–524. doi: 10.1016/S1474-4422(14)70030-4.
  74. van Middelaar T, Nederkoorn PJ, van der Worp HB, Stam J, Richard E. Quality of life after surgical decompression for space-occupying middle cerebral artery infarction: systematic review. *Int J Stroke*. 2015;10:170–176. doi: 10.1111/ijvs.12329.
  75. Creutzfeldt CJ, Holloway RG, Walker M. Symptomatic and palliative care for stroke survivors [published correction appears in *J Gen Intern Med*. 2014;29:1715]. *J Gen Intern Med*. 2012;27:853–860. doi: 10.1007/s11606-011-1966-4.
  76. Cristian A, Giammarino C, Olds M, Adams E, Moriarty C, Ratner S, Mural S, Stobart EC. Safety considerations for patients with communication disorders in rehabilitation medicine settings. *Phys Med Rehabil Clin N Am*. 2012;23:343–347. doi: 10.1016/j.pmr.2012.02.017.
  77. Hansen AP, Marcussen NS, Klit H, Andersen G, Finnerup NB, Jensen TS. Pain following stroke: a prospective study. *Eur J Pain*. 2012;16:1128–1136. doi: 10.1002/j.1532-2149.2012.00123.x.
  78. Guajardo VD, Terroni L, Sobreiro Mde F, Zerbini MI, Tinone G, Scaff M, Iosifescu DV, de Lucia MC, Fráguas R. The influence of depressive symptoms on quality of life after stroke: a prospective study. *J Stroke Cerebrovasc Dis*. 2015;24:201–209. doi: 10.1016/j.jstrokecerebrovasdis.2014.08.020.
  79. Chen YK, Qu JF, Xiao WM, Li WY, Weng HY, Li W, Liu YL, Luo GP, Fang XW, Ungvari GS, Xiang YT. Poststroke fatigue: risk factors and its effect on functional status and health-related quality of life. *Int J Stroke*. 2015;10:506–512. doi: 10.1111/ijvs.12409.

80. Hackett ML, Anderson CS. Predictors of depression after stroke: a systematic review of observational studies. *Stroke*. 2005;36:2296–2301. doi: 10.1161/01.STR.0000183622.75135.a4.
81. Friefeld SJ, Westmacott R, Macgregor D, Deveber GA. Predictors of quality of life in pediatric survivors of arterial ischemic stroke and cerebral sinovenous thrombosis. *J Child Neurol*. 2011;26:1186–1192. doi: 10.1177/0883073811408609.
82. Haley WE, Roth DL, Hovater M, Clay OJ. Long-term impact of stroke on family caregiver well-being: a population-based case-control study. *Neurology*. 2015;84:1323–1329. doi: 10.1212/WNL.0000000000001418.
83. de Kloet AJ, Lambregts SA, Berger MA, van Markus F, Wolterbeek R, Vliet Vlieland TP. Family impact of acquired brain injury in children and youth. *J Dev Behav Pediatr*. 2015;36:342–351. doi: 10.1097/DBP.0000000000000169.
84. Creutzfeldt CJ, Holloway RG. Treatment decisions after severe stroke: uncertainty and biases. *Stroke*. 2012;43:3405–3408. doi: 10.1161/STROKEAHA.112.673376.
85. Bakas T, Clark PC, Kelly-Hayes M, King RB, Lutz BJ, Miller EL; on behalf of the American Heart Association Council on Cardiovascular and Stroke Nursing and the Stroke Council. Evidence for stroke family caregiver and dyad interventions: a statement for healthcare professionals from the American Heart Association and American Stroke Association. *Stroke*. 2014;45:2836–2852. doi: 10.1161/STR.0000000000000033.
86. Post SG, Puchalski CM, Larson DB. Physicians and patient spirituality: professional boundaries, competency, and ethics. *Ann Intern Med*. 2000;132:578–583. doi: 10.7326/0003-4819-132-7-200004040-00010.
87. Wee B, Adams A, Eva G. Palliative and end-of-life care for people with stroke. *Curr Opin Support Palliat Care*. 2010;4:229–232. doi: 10.1097/SPC.0b013e32833ff4f8.
88. Heart Failure Society of America, Lindenfeld J, Albert NM, Boehmer JP, Collins SP, Ezekowitz JA, Givertz MM, Katz SD, Klapholz M, Moser DK, Rogers JG, Starling RC, Stevenson WG, Tang WH, Teerlink JR, Walsh MN. HFSA 2010 comprehensive heart failure practice guideline. *J Card Fail*. 2010;16:e1–e194. doi: 10.1016/j.cardfail.2010.04.004.
89. Johnson MJ, Houghton T. Palliative care for patients with heart failure: description of a service. *Palliat Med*. 2006;20:211–214.
90. Selman L, Harding R, Beynon T, Hodson F, Coady E, Hazeldine C, Walton M, Gibbs L, Higginson IJ. Improving end-of-life care for patients with chronic heart failure: “Let’s hope it’ll get better, when I know in my heart of hearts it won’t.” *Heart*. 2007;93:963–967. doi: 10.1136/hrt.2006.106518.
91. Selman L, Harding R, Beynon T, Hodson F, Hazeldine C, Coady E, Gibbs L, Higginson IJ. Modelling services to meet the palliative care needs of chronic heart failure patients and their families: current practice in the UK. *Palliat Med*. 2007;21:385–390. doi: 10.1177/0269216307077698.
92. McKenna M, Clark SC. Palliative care in cardiopulmonary transplantation. *BMJ Support Palliat Care*. 2015;5:427–434. doi: 10.1136/bmjspcare-2014-000769.
93. Muhandiramge D, Udeoji DU, Biswas OS, Bharadwaj P, Black LZ, Mulholland KA, Moschella C, Schwarz ER. Palliative care issues in heart transplant candidates. *Curr Opin Support Palliat Care*. 2015;9:5–13. doi: 10.1097/SPC.0000000000000112.
94. The Joint Commission. VAD Certification. 2015. <http://www.jointcommission.org/search/default.aspx?Keywords=vad&certification&f=sitename&sitename=Joint+Commission>. Accessed July 20, 2015.
95. Swetz KM, Ottenberg AL, Freeman MR, Mueller PS. Palliative care and end-of-life issues in patients treated with left ventricular assist devices as destination therapy. *Curr Heart Fail Rep*. 2011;8:212–218. doi: 10.1007/s11897-011-0060-x.
96. Hupcey JE, Fenstermacher K, Kitko L, Fogg J. Palliative needs of spousal caregivers of patients with heart failure followed at specialized heart failure centers. *J Hosp Palliat Nurs*. 2011;13:142–150. doi: 10.1097/NJH.0b013e31820ce15e.
97. Iacovetto MC, Matlock DD, McIvannan CK, Thompson JS, Bradley W, LaRue SJ, Allen LA. Educational resources for patients considering a left ventricular assist device: a cross-sectional review of internet, print, and multimedia materials. *Circ Cardiovasc Qual Outcomes*. 2014;7:905–911. doi: 10.1161/CIRCOUTCOMES.114.000892.
98. Bekelman DB, Nowels CT, Retrum JH, Allen LA, Shakar S, Hutt E, Heyborne T, Main DS, Kutner JS. Giving voice to patients’ and family caregivers’ needs in chronic heart failure: implications for palliative care programs. *J Palliat Med*. 2011;14:1317–1324. doi: 10.1089/jpm.2011.0179.
99. Strachan PH, Ross H, Rocker GM, Dodek PM, Heyland DK; Canadian Researchers at the End of Life Network (CARENET). Mind the gap: opportunities for improving end-of-life care for patients with advanced heart failure. *Can J Cardiol*. 2009;25:635–640.
100. Warraich HJ. Failing patients with heart failure. *New York Times*. 2015. [http://www.nytimes.com/2015/08/10/opinion/failing-patients-with-heart-failure.html?\\_r=1](http://www.nytimes.com/2015/08/10/opinion/failing-patients-with-heart-failure.html?_r=1). Accessed August 25, 2015.
101. Garland EL, Bruce A, Stajduhar K. Exposing barriers to end-of-life communication in heart failure: an integrative review. *Can J Cardiovasc Nurs*. 2013;23:12–18.
102. Hjelmfors L, Strömberg A, Friedrichsen M, Mårtensson J, Jaarsma T. Communicating prognosis and end-of-life care to heart failure patients: a survey of heart failure nurses’ perspectives. *Eur J Cardiovasc Nurs*. 2014;13:152–161. doi: 10.1177/1474515114521746.
103. Metzger M, Norton SA, Quinn JR, Gramling R. Patient and family members’ perceptions of palliative care in heart failure. *Heart Lung*. 2013;42:112–119. doi: 10.1016/j.hrtlng.2012.11.002.
104. Chen CY, Thorsteinsdottir B, Cha SS, Hanson GJ, Peterson SM, Rahman PA, Naessens JM, Takahashi PY. Health care outcomes and advance care planning in older adults who receive home-based palliative care: a pilot cohort study. *J Palliat Med*. 2015;18:38–44. doi: 10.1089/jpm.2014.0150.
105. Wright AA, Zhang B, Ray A, Mack JW, Trice E, Balboni T, Mitchell SL, Jackson VA, Block SD, Maciejewski PK, Prigerson HG. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA*. 2008;300:1665–1673. doi: 10.1001/jama.300.14.1665.
106. Garrido MM, Prigerson HG. The end-of-life experience: modifiable predictors of caregivers’ bereavement adjustment. *Cancer*. 2014;120:918–925. doi: 10.1002/cncr.28495.
107. Hefner JE, Barbieri C. End-of-life care preferences of patients enrolled in cardiovascular rehabilitation programs. *Chest*. 2000;117:1474–1481.
108. Physician Orders for Life-Sustaining Treatment Program. <http://www.polst.org/>. Accessed January 6, 2016.
109. Fendler TJ, Swetz KM, Allen LA. Team-based palliative and end-of-life care for heart failure. *Heart Fail Clin*. 2015;11:479–498. doi: 10.1016/j.hfc.2015.03.010.
110. Pediatric My Wishes. <https://www.agingwithdignity.org/shop/product-details/pediatric-my-wishes>. Accessed June 20, 2016.
111. Voicing My Choices: A Planning Guide for Adolescents & Young Adults. <https://agingwithdignity.org/shop/product-details/voicing-my-choices>. Accessed June 20, 2016.
112. Schwarz ER, Baraghoush A, Morrissey RP, Shah AB, Shinde AM, Phan A, Bharadwaj P. Pilot study of palliative care consultation in patients with advanced heart failure referred for cardiac transplantation. *J Palliat Med*. 2012;15:12–15. doi: 10.1089/jpm.2011.0256.

113. Rugno FC, Paiva BS, Paiva CE. Early integration of palliative care facilitates the discontinuation of anticancer treatment in women with advanced breast or gynecologic cancers. *Gynecol Oncol*. 2014;135:249–254. doi: 10.1016/j.ygyno.2014.08.030.
114. Steele LL, Mills B, Hardin SR, Hussey LC. The quality of life of hospice patients: patient and provider perceptions. *Am J Hosp Palliat Care*. 2005;22:95–110. doi: 10.1177/104990910502200205.
115. Connor SR, Pyenson B, Fitch K, Spence C, Iwasaki K. Comparing hospice and nonhospice patient survival among patients who die within a three-year window. *J Pain Symptom Manage*. 2007;33:238–246. doi: 10.1016/j.jpainsymman.2006.10.010.
116. Teno JM, Plotzke M, Gozalo P, Mor V. A national study of live discharges from hospice. *J Palliat Med*. 2014;17:1121–1127. doi: 10.1089/jpm.2013.0595.
117. Leow M, Chan S, Chan M. A pilot randomized, controlled trial of the effectiveness of a psychoeducational intervention on family caregivers of patients with advanced cancer. *Oncol Nurs Forum*. 2015;42:E63–E72. doi: 10.1188/15.ONF.E63-E72.
118. Seaman JB, Bear TM, Documet PI, Sereika SM, Albert SM. Hospice and family involvement with end-of-life care: results from a population-based survey. *Am J Hosp Palliat Care*. 2016;33:130–135. doi: 10.1177/1049909114550392.
119. Sekelja N, Butow PN, Tattersall MH. Bereaved cancer carers' experience of and preference for palliative care. *Support Care Cancer*. 2010;18:1219–1228. doi: 10.1007/s00520-009-0752-x.
120. Abernethy AP, Currow DC, Fazekas BS, Luszcz MA, Wheeler JL, Kuchibhatla M. Specialized palliative care services are associated with improved short- and long-term caregiver outcomes. *Support Care Cancer*. 2008;16:585–597. doi: 10.1007/s00520-007-0342-8.
121. Hwang B, Fleischmann KE, Howie-Esquivel J, Stotts NA, Dracup K. Caregiving for patients with heart failure: impact on patients' families. *Am J Crit Care*. 2011;20:431–441; quiz 442. doi: 10.4037/ajcc2011472.
122. Wright AA, Keating NL, Balboni TA, Matulonis UA, Block SD, Prigerson HG. Place of death: correlations with quality of life of patients with cancer and predictors of bereaved caregivers' mental health. *J Clin Oncol*. 2010;28:4457–4464. doi: 10.1200/JCO.2009.26.3863.
123. Sadler E, Hales B, Henry B, Xiong W, Myers J, Wynnychuk L, Taggar R, Heyland D, Fowler R. Factors affecting family satisfaction with inpatient end-of-life care. *PLoS One*. 2014;9:e110860. doi: 10.1371/journal.pone.0110860.
124. Pottie CG, Burch KA, Thomas LP, Irwin SA. Informal caregiving of hospice patients. *J Palliat Med*. 2014;17:845–856. doi: 10.1089/jpm.2013.0196.
125. McMillan SC, Mahon M. The impact of hospice services on the quality of life of primary caregivers. *Oncol Nurs Forum*. 1994;21:1189–1195.
126. Lorenz KA, Lynn J, Dy SM, Shugarman LR, Wilkinson A, Mularski RA, Morton SC, Hughes RG, Hilton LK, Maglione M, Rhodes SL, Rolon C, Sun VC, Shekelle PG. Evidence for improving palliative care at the end of life: a systematic review [published correction appears in *Arch Intern Med*. 2009;151:674]. *Ann Intern Med*. 2008;148:147–159. doi: 10.7326/0003-4819-148-2-200801150-00010.
127. Gomes B, Calanzani N, Curiale V, McCrone P, Higginson IJ. Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. *Cochrane Database Syst Rev*. 2013;6:CD007760. doi: 10.1002/14651858.CD007760.pub2.
128. O'Hara RE, Hull JG, Lyons KD, Bakitas M, Hegel MT, Li Z, Ahles TA. Impact on caregiver burden of a patient-focused palliative care intervention for patients with advanced cancer. *Palliat Support Care*. 2010;8:395–404. doi: 10.1017/S1478951510000258.
129. Mitchell GK, Del Mar CB, O'Rourke PK, Clavarino AM. Do case conferences between general practitioners and specialist palliative care services improve quality of life? A randomised controlled trial (ISRCTN 52269003). *Palliat Med*. 2008;22:904–912. doi: 10.1177/0269216308096721.
130. Dudgeon DJ, Knott C, Eichholz M, Gerlach JL, Chapman C, Viola R, Van Dijk J, Preston S, Batchelor D, Bartfay E. Palliative Care Integration Project (PCIP) quality improvement strategy evaluation. *J Pain Symptom Manage*. 2008;35:573–582. doi: 10.1016/j.jpainsymman.2007.07.013.
131. Weitzner MA, McMillan SC, Jacobsen PB. Family caregiver quality of life: differences between curative and palliative cancer treatment settings. *J Pain Symptom Manage*. 1999;17:418–428. doi: http://dx.doi.org/10.1016/S0885-3924(99)00014-7.
132. Kaasalainen S, Strachan PH, Brazil K, Marshall D, Willison K, Dolovich L, Taniguchi A, Demers C. Managing palliative care for adults with advanced heart failure. *Can J Nurs Res*. 2011;43:38–57.
133. Fahlberg BB, Weigand D, Wingate S. Palliative and hospice management of heart failure. In: Paul S, ed. *Heart Failure Disease Management: From Planning to Implementation*. Mt Laurel, NJ: American Association of Heart Failure Nurses; 2014:179–205.
134. Unroe KT, Greiner MA, Hernandez AF, Whellan DJ, Kaul P, Schulman KA, Peterson ED, Curtis LH. Resource use in the last 6 months of life among Medicare beneficiaries with heart failure, 2000–2007. *Arch Intern Med*. 2011;171:196–203. doi: 10.1001/archinternmed.2010.371.
135. Wiegand DL, Kalowes PG. Withdrawal of cardiac medications and devices. *AACN Adv Crit Care*. 2007;18:415–425. doi: 10.1097/01.AACN.0000298634.45653.81.
136. Goldstein N, Carlson M, Livote E, Kutner JS. Brief communication: management of implantable cardioverter-defibrillators in hospice: a nationwide survey. *Ann Intern Med*. 2010;152:296–299. doi: 10.7326/0003-4819-152-5-201003020-00007.
137. Lampert R, Hayes DL, Annas GJ, Farley MA, Goldstein NE, Hamilton RM, Kay GN, Kramer DB, Mueller PS, Padeletti L, Pozuelo L, Schoenfeld MH, Vardas PE, Wiegand DL, Zellner R; American College of Cardiology; American Geriatrics Society; American Academy of Hospice and Palliative Medicine; American Heart Association; European Heart Rhythm Association; Hospice and Palliative Nurses Association. HRS Expert Consensus Statement on the Management of Cardiovascular Implantable Electronic Devices (CIEDs) in patients nearing end of life or requesting withdrawal of therapy. *Heart Rhythm*. 2010;7:1008–1026. doi: 10.1016/j.hrthm.2010.04.033.
138. MacIver J, Ross HJ. Withdrawal of ventricular assist device support. *J Palliat Care*. 2005;21:151–156.
139. Allen JY, Haley WE, Small BJ, Schonwetter RS, McMillan SC. Bereavement among hospice caregivers of cancer patients one year following loss: predictors of grief, complicated grief, and symptoms of depression. *J Palliat Med*. 2013;16:745–751. doi: 10.1089/jpm.2012.0450.
140. Chau NG, Zimmermann C, Ma C, Taback N, Krzyzanowska MK. Bereavement practices of physicians in oncology and palliative care. *Arch Intern Med*. 2009;169:963–971. doi: 10.1001/archinternmed.2009.118.
141. Granek L, Mazzotta P, Tozer R, Krzyzanowska MK. Oncologists' protocol and coping strategies in dealing with patient loss. *Death Stud*. 2013;37:937–952. doi: 10.1080/07481187.2012.692461.
142. Ahluwalia SC, Fried TR. Physician factors associated with outpatient palliative care referral. *Palliat Med*. 2009;23:608–615. doi: 10.1177/0269216309106315.
143. Coalition to Transform Advanced Care. Policy framework. <http://www.thectac.org/wp-content/uploads/2014/10/Policy-Framework.pdf>. Accessed January 6, 2016.
144. CMS Hospice Conditions of Participation, 42 CFR §418.20 (2016).
145. CMS Hospice Conditions of Participation, 42 CFR §418.22 (2016).
146. Revisions to Payment Policies Under the Physician Fee Schedule and Other Revisions to Part B for CY 2016, 80 FR 220:70866–71386 (2015).

147. Centers for Medicare & Medicaid Services. Medicare Care Choices Model. 2015. <http://innovation.cms.gov/initiatives/Medicare-Care-Choices/>. Accessed September 17, 2015.
148. Sahlen KG, Boman K, Brännström M. A cost-effectiveness study of person-centered integrated heart failure and palliative home care: based on a randomized controlled trial. *Palliat Med*. 2016;30:296–302. doi: 10.1177/0269216315618544.
149. May P, Normand C, Morrison RS. Economic impact of hospital inpatient palliative care consultation: review of current evidence and directions for future research. *J Palliat Med*. 2014;17:1054–1063. doi: 10.1089/jpm.2013.0594.
150. Morrison RS, Penrod JD, Cassel JB, Caust-Ellenbogen M, Litke A, Spragens L, Meier DE; Palliative Care Leadership Centers' Outcomes Group. Cost savings associated with US hospital palliative care consultation programs. *Arch Intern Med*. 2008;168:1783–1790. doi: 10.1001/archinte.168.16.1783.
151. Smith S, Brick A, O'Hara S, Normand C. Evidence on the cost and cost-effectiveness of palliative care: a literature review. *Palliat Med*. 2014;28:130–150. doi: 10.1177/0269216313493466.
152. Centers for Medicare & Medicaid Services. Medicare and You Handbook. <https://www.medicare.gov/forms-help-and-resources/mail-about-medicare/about-medicare-and-you.html>. Accessed June 20, 2016.
153. Retooling the Healthcare Workforce for an Aging America Act of 2009, S 245, 111th Cong (2009). <https://www.govtrack.us/congress/bills/111/hr468/text/ih>. Accessed June 20, 2016.
- 153a. Retooling the Healthcare Workforce for an Aging America Act of 2009, HR 468, 111th Cong (2009). <https://www.govtrack.us/congress/bills/111/hr468/text/ih>. Accessed June 20, 2016.
- 153b. Advance Planning and Compassionate Care Act of 2009, HR 2911, 111th Cong (2009). <https://www.govtrack.us/congress/bills/111/hr468/text/ih>. Accessed June 20, 2016.
- 153c. Advance Planning and Compassionate Care Act of 2009, S1150, 111th Cong (2009). <https://www.govtrack.us/congress/bills/111/hr468/text/ih>. Accessed June 20, 2016.
154. Advance Planning and Compassionate Care Act of 2009, HR 2911, 111th Cong (2009). <https://www.gpo.gov/fdsys/pkg/BILLS-111s1150is/pdf/BILLS-111s1150is.pdf>. Accessed June 20, 2016.
- 154a. Advance Planning and Compassionate Care Act of 2009, S 1150, 111th Cong (2009). <https://www.gpo.gov/fdsys/pkg/BILLS-111s1150is/pdf/BILLS-111s1150is.pdf>. Accessed June 20, 2016.
155. American Heart Association/American Stroke Association. Principles for Palliative Care. September 2013. [https://www.heart.org/idc/groups/ahaec-public/@wcm/@adv/documents/downloadable/ucm\\_467599.pdf](https://www.heart.org/idc/groups/ahaec-public/@wcm/@adv/documents/downloadable/ucm_467599.pdf). Accessed July 28, 2015.
156. NYS Public Health Law, § 2007-C, added by L. 2010 Ch. 331 (A07617).
157. Palliative Care Access Act, 2011 NY Pub Health Laws chap 59 sec 2997-d. [http://www.health.ny.gov/regulations/public\\_health\\_law/section/2997d/](http://www.health.ny.gov/regulations/public_health_law/section/2997d/). Accessed July 20, 2015.
158. State License CME/CE Requirements for Physicians, Nurse Practitioners, and Physician Assistants. <http://www.mycme.com/state-licensing-cmece-requirements/section/3858/>. Accessed July 20, 2015.
159. Stjernswärd J, Foley KM, Ferris FD. The public health strategy for palliative care. *J Pain Symptom Manage*. 2007;33:486–493. doi: 10.1016/j.jpainsymman.2007.02.016.
160. Pain & Policy Studies Group, University of Wisconsin Carbone Cancer Center. Achieving balance in state pain policy: a progress report card (CY 2013). <http://www.painpolicy.wisc.edu/sites/www.painpolicy.wisc.edu/files/prc2013.pdf>. Accessed May 20, 2016.
161. Deyo RA, Irvine JM, Millet LM, Beran T, O'Kane N, Wright DA, McCarty D. Measures such as interstate cooperation would improve the efficacy of programs to track controlled drug prescriptions. *Health Aff (Millwood)*. 2013;32:603–613. doi: 10.1377/hlthaff.2012.0945.
162. Institute of Medicine. *Crisis Standards of Care: A Systems Framework for Catastrophic Disaster Response*. Washington, DC: National Academies Press; 2012.
163. Center to Advance Palliative Care website. <http://www.capc.org>. Accessed August 20, 2015.
164. Youth Transitions Collaborative. Transition QuickGuide: Take Charge of Planning and Managing Your Own Health and Career Goals. <http://www.gottransition.org/resourceGet.cfm?id=372>. Accessed August 20, 2015.
165. American Board of Internal Medicine. Hospice and palliative medicine policies. <http://www.abim.org/certification/policies/imss/hospice.aspx>. Accessed August 20, 2015.
166. Hospice and Palliative Credentialing Center website. <http://hpcc.advancingexpertcare.org/#>. Accessed August 20, 2015.
167. National Association of Social Workers. The Advanced Certified Hospice and Palliative Social Worker (ACHP-SW). <https://www.socialworkers.org/credentials/credentials/achp.asp>. Accessed August 20, 2015.
168. Board of Chaplaincy Certification Inc. BCCI Certification. <http://bcciprofessionalchaplains.org/content.asp?pl=25&contentid=25>. Accessed August 20, 2015.