



Palliative Care

Reducing Suffering for Patients with Heart Disease & Stroke

BACKGROUND

The American Heart Association defines palliative care as patient- and family-centered care that optimizes health-related quality of life (HRQOL) by anticipating, preventing, and treating suffering.¹ It focuses on communication, shared decision-making about treatment options, advance-care planning, and attention to physical, emotional, spiritual, and psychological distress and includes the patient's family and care system.¹ Palliative care is not the same as hospice or end-of-life care (although palliative care is always provided with hospice care) and can be provided any time relief from symptoms and stress of a serious diagnosis is needed.² Along with patients and their families, specialty palliative-care teams collaborate with the patient's physicians on the most relevant and current treatments and medical management appropriate to the complexity of the condition.¹ (Palliative care does not limit patients' treatment options.) Integral to palliative care is the support structure comprised of a range of key stakeholders and medical professionals (Figure 1).

LANDSCAPE

Palliative care helps patients and families face the long-term challenges and burden of advanced cardiovascular disease (CVD) and stroke.¹ It is appropriate for many cardiovascular diseases, including heart failure, congenital syndromes, and congenital anomalies, and their associated symptoms of fatigue,¹ depression,^{3,4} shortness of breath,⁵ pain,⁵ edema,⁵ insomnia,⁶ anxiety,⁵ cognitive impairment,⁷ anorexia,⁵ and social isolation.⁵ Stroke survivors and patients with advanced heart failure in particular sometimes experience poor HRQOL as a result of deteriorating health, symptom distress, and complex care regimens.^{1,8,9} Family members, who often act as primary caregivers, can experience psychological stress as they deal with physical, emotional, and cognitive changes in their loved one.^{1,10} Intended to alleviate symptoms and to manage pain at any stage of disease, palliative care should be incorporated early in the disease trajectory by the patient's primary care team or specialty palliative care providers¹ and as an ongoing component of disease-modifying treatment.¹¹

Benefits of Palliative Care

Integrating palliative care in the management of advanced CVD and stroke patients may provide the following benefits:

- Improved patient and caregiver understanding of disease, treatment and prognosis,¹
- Improved treatment of symptoms and relief of suffering,¹
- Shared-decision making based on patient values, preferences and goals,¹
- Enhanced patient-clinician communication,¹
- Individual advance care-planning based on benefits, risks, and burdens of care,¹
- Improved patient and caregiver outcomes,¹
- Improved preparation for end-of-life and associated care,¹ and
- Bereavement support.¹

Barriers to Palliative Care

Patients also face barriers to getting palliative care, including:

- Reluctance of health care professionals to refer patients to palliative care because of their lack of knowledge about benefits and/or availability of palliative care services,¹
- A shortage of palliative-care clinicians,¹²

Figure 1: Palliative Care Support Structure³



FACT SHEET: Palliative Care

- Clinician discomfort in communicating with patients and families about palliative care¹ and lack of training in communicating need for palliative care,¹¹
- Limitations in payment systems for comprehensive palliative care services,¹ and
- Family dynamics, culture, religion, and language differences.⁸

Access to palliative care in rural areas is more difficult than in urban areas: only 17% of rural hospitals with fifty+ beds have a palliative care program while 90% of hospitals with palliative care programs are in urban areas.¹³ In addition, disparities in access to palliative care adversely impact communities of color, people with low income, and sexual minorities (i.e., lesbian, gay, bisexual, and transgender individuals).¹⁴

Most private insurance plans, as well as Medicare and Medicaid, cover palliative care services, although there may be restrictions such as seeing an in-network provider and prior-authorization requirements for palliative procedures and medications.

THE ASSOCIATION ADVOCATES

Patients' awareness of, and access to, palliative care interventions align with the mission and goals of the AHA and American Stroke Association. 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 advocates for policies that:

- Encourage federal and state agencies to reimburse for comprehensive delivery of palliative care services, inclusive of palliative care treatment for patients with stroke and CVD,
- Support strong payer-provider relationships that involve data sharing in order to identify patients in need of palliative care and support care coordination,
- Identify better care and payment models, and establish quality standards and outcome measurement,
- Address 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,
- Promote coordination of care planning, treatment decision-making, and discharge planning processes for patients, as well as feasible care plans that reflect patients' palliative care needs, during transitions and across care settings,
- Respond to the need for healthcare professionals' education and training in palliative care as part of licensure requirements for those who provide care to CVD and stroke patients, as well as efforts to increase the number of healthcare professionals with specialty certification, and
- Test and evaluate models of palliative care-delivery to improve care for the sickest, most vulnerable beneficiaries.

For more information on specific policy recommendations endorsed by the the American Heart Association, please visit www.heart.org/en/get-involved/advocate/policy-research.

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