Circulation

AHA SCIENTIFIC STATEMENT

Palliative Care and Advanced Cardiovascular Disease in Adults: Not Just End-of-Life Care: A Scientific Statement From the American Heart Association

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ABSTRACT: Cardiovascular disease remains a leading cause of morbidity and mortality in adults despite recent scientific advancements. Although people are living longer lives, there may be an adverse impact on quality of life, necessitating a greater need for palliative care services and support. Palliative care for adults with advanced cardiovascular disease has the potential to significantly improve quality of life for individuals living with cardiovascular disease and their informal care partners. Effective communication, shared decision-making, age-friendly care principles, and advance care planning are vital components of palliative care and support comprehensive and holistic care throughout the advanced cardiovascular disease trajectory and across care settings. Current evidence highlights the benefits of palliative care in managing symptoms, reducing psychological distress, and supporting both people with cardiovascular disease and their care partners. However, significant gaps exist in palliative care research related to non–heart failure populations, care partner outcomes, and palliative care implementation in diverse populations. This scientific statement (1) discusses the application of effective communication, shared decision-making, age-friendly care, and advance care planning in advanced cardiovascular disease palliative care; (2) provides a summary of recent evidence related to palliative care and symptom management, quality of life, spiritual and psychological support, and bereavement support in individuals with advanced cardiovascular disease and their care partners; (3) discusses issues involving diversity, equity, and inclusion in cardiovascular disease palliative care; (4) highlights the ethical and legal concerns surrounding palliative care and implanted cardiac devices; and (5) provides strategies for palliative care engagement in adults with advanced cardiovascular disease for the care team.

Key Words: AHA Scientific Statements ■ advance care planning ■ cardiovascular diseases ■ caregivers ■ communication ■ decision making, shared ■ palliative care ■ quality of life

Individuals with advanced cardiovascular disease (CVD) are living longer, thanks to scientific advances in management. However, advanced CVD remains a leading cause of morbidity and mortality, and the number of individuals in need of palliative care (PC) is much higher than that of people who receive it.[1,2] The American Heart Association supports increased access to high-quality, evidence-based PC.[3,4] PC involves a multidisciplinary approach that is person and family centered and focuses on preventing and treating physical, psychological, social, and spiritual problems that adversely affect quality of life (QOL). PC is appropriate throughout the advanced CVD trajectory and should be incorporated across all care settings.[5] In essence, PC is more than just end-of-life care.

When initiated early, PC can be vital in maintaining QOL through access to interdisciplinary health care professionals with collaborative roles to support individuals with advanced CVD and their families.[5] Primary PC refers to the care team's role in aiding individuals' and families' understanding of the disease

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course, addressing potential complications and associated morbidity, supporting problem-solving for QOL issues (eg, symptom management, mental distress), and shared decision-making throughout the illness spectrum. Specialty (secondary) PC is provided by clinicians who are trained and certified in advanced decision-making, transition to end-of-life care or hospice, and bereavement support and often consult on complex physical or emotional problems.[5,6] However, a worldwide shortage of practitioners specially trained in PC remains,[7] highlighting the importance of the care team's role in providing primary PC support in everyday clinical care.

PC in advanced CVD includes 4 essential and intertwined components: the person with CVD–family–clinician communication, shared decision-making, age-friendly care, and advance care planning. These components guide the critical PC domains of symptom management, QOL, spiritual and psychological support, and bereavement support (Figure 1). Effective communication is critical to providing culturally competent and holistic PC, which involves the person and family in the care process across all care settings and throughout the disease trajectory.[8] Effective communication is also instrumental in facilitating shared decision-making, age-friendly care, and advance care planning.[4,9–11] Several evidence-based recommendations to improve communication between the care team and the person/family illustrate the importance of timing and open communication throughout the illness spectrum (Figure 2).[8] Likewise, the care teams must maintain cultural sensitivity when communicating with individuals and families about decision-making and end of life across a spectrum of collectivist cultures to avoid missteps that may impede successful care.[12]

Shared decision-making involves a collaborative and communicative process among the person, family, and care team. It includes vital elements supporting personal autonomy on important health care decisions throughout the illness, including everyday care, treatment approach,

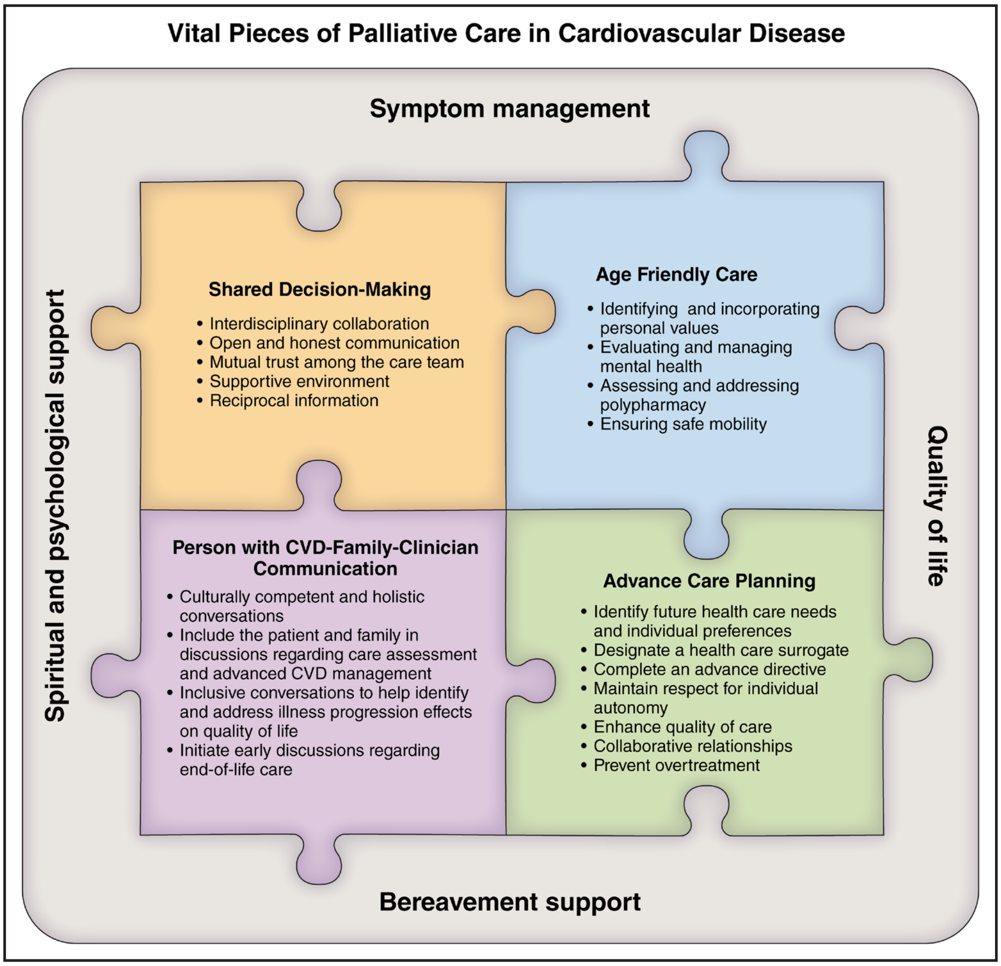
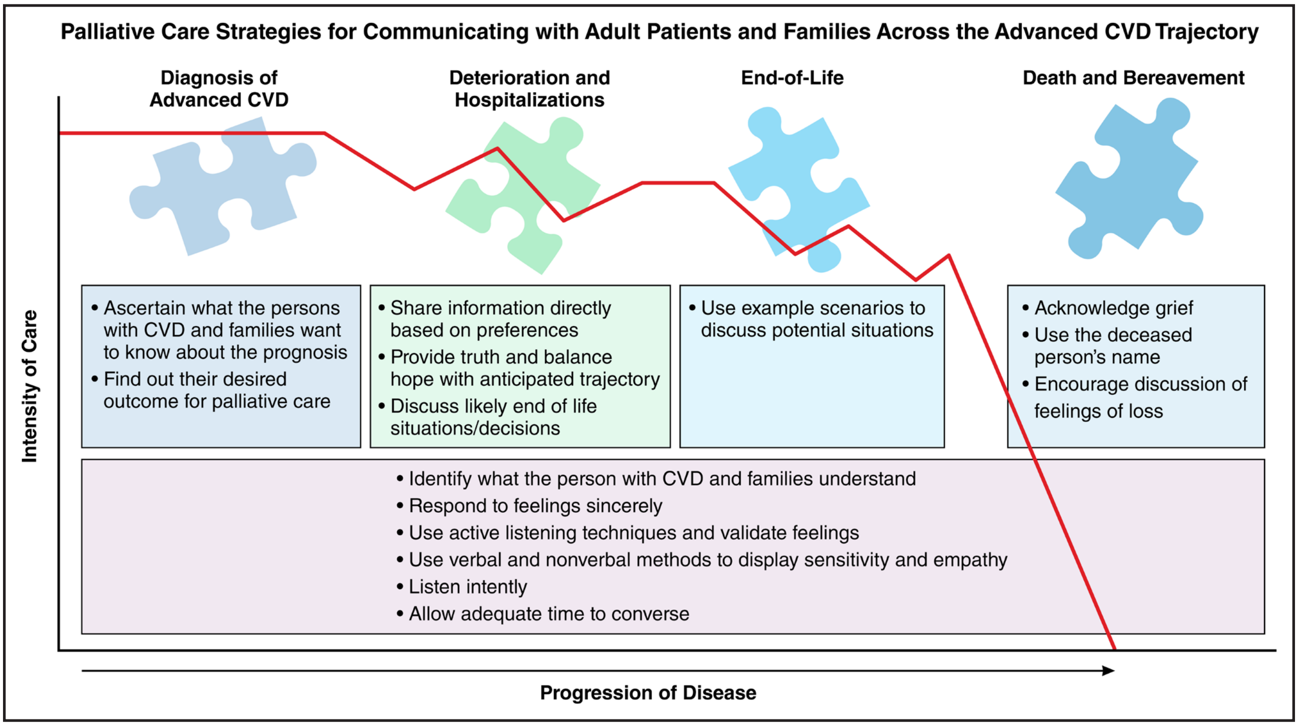


Figure 1. Vital pieces of PC in CVD.

Palliative care (PC) in adults with advanced cardiovascular disease (CVD) involves 4 necessary pieces: shared decision-making, age-friendly care, effective person with CVD–family–clinician communication, and advance care planning. Each of these critical pieces includes specific activities that, when instituted in clinical practice, contribute to key PC domains of symptom management, quality of life, spiritual and psychological support, and bereavement support.



- Ascertain what the persons with CVD and families want to know about the prognosis
- Find out their desired outcome for palliative care

- Share information directly based on preferences
- Provide truth and balance hope with anticipated trajectory
- Discuss likely end of life situations/decisions

- Use example scenarios to discuss potential situations

- Acknowledge grief
- Use the deceased person's name
- Encourage discussion of feelings of loss

- Identify what the person with CVD and families understand
- Respond to feelings sincerely
- Use active listening techniques and validate feelings
- Use verbal and nonverbal methods to display sensitivity and empathy
- Listen intently
- Allow adequate time to converse

Figure 2. PC strategies for communicating with adult patients and families across the advanced CVD trajectory.
Effective communication among the person with cardiovascular disease (CVD), family, and clinician is critical to providing culturally competent and holistic palliative care (PC). To achieve this, we suggest strategies that are appropriate for use when communicating with adults with CVD and their families that are based on the intensity of care and progression of disease.

symptom management, and end-of-life preferences.[4,13] Failure of the care team to successfully facilitate shared decision-making can result in discordance between individuals with advanced CVD and their families and lead to relational conflict, which undermines not only successful PC but all care.[14]

Age-friendly care refers to health care that is inclusive and receptive to the needs and desires of older adults to improve QOL.[9,10] The key principles of age-friendly care can substantially affect the illness trajectory and should be included in PC for advanced CVD, regardless of age, to support healthy aging with a chronic illness, especially with the notable increases in life expectancy for individuals with advanced CVD.[1] Incorporating age-friendly care is one way to support individualized PC and to provide a bridge between health systems and primary PC, and age-friendly care can be used to address common issues such as multimorbidity, polypharmacy, and cognitive impairment.[9,10] Although age-friendly care is frequently endorsed by geriatricians, there continues to be minimal uptake in the cardiovascular field, despite the significant overlap in populations.[15,16] Leading organizations[9,10] advocate for the inclusion of age-friendly care principles, commonly known as the 4 Ms (what matters, medication, mentation, mobility), in PC. There is an overlap between age-friendly care principles and other PC essentials. Age-friendly care tends to focus on functionality compared with symptoms. However, symptoms significantly affect functionality and influence QOL, thereby playing a considerable role in shared decision-making and advance care planning discussions. Thus, including age-friendly care is crucial to enhancing QOL and addressing age-related factors that may influence PC outcomes.[16]

However, identifying "what matters" does not necessarily lead to the development of an advance directive or the appointment of a health care surrogate, both important aspects of advance care planning. Advance care planning involves communicating with individuals and others to plan future health care needs and preferences.[11] Thus, elements of effective communication, shared decision-making, and age-friendly care are woven throughout advance care planning. Key family members, often informal care partners and significant others, should be included in these discussions so that the person with advanced CVD, family, and health care practitioners fully understand the person's present and future desires for their medical treatment. Inclusion of informal care partners (hereafter referred to as care partners) in these discussions is critical because they are often spouses/partners or other close family members who provide daily care for the person with advanced CVD. Before beginning conversations, the care team should assess the individual's and family's readiness, openness, and ambivalence[17] because timing is essential in effective advance care planning. Successful advance care planning can greatly affect QOL, care satisfaction, and the quality of communication between individuals with advanced CVD and their families.[18]

PC AND ADVANCED CVD

Types of Advanced CVD That May Benefit From PC

Multiple cardiovascular pathologies can lead to clinical scenarios that benefit from PC.[3,19–21] Currently, the engagement of PC for advanced CVD often involves the ramping up of services from the early stages of diagnosis to increased involvement as disease severity, functional limitations, and frailty increase, with the primary focus being on decreasing the symptom experience and improving QOL.

PC is commonly used for advanced heart failure (HF). Advanced HF is marked by symptoms of dyspnea, edema, and fatigue but can also include arrhythmias and associated defibrillator shocks, organ dysfunction requiring dialysis, thrombotic complications, depression, and anxiety. Because of the physical and mental sequelae associated with HF, leading cardiovascular organizations, including the American Heart Association, recommend that PC be provided throughout the HF trajectory, with specialty PC practitioners included in the care team that supports advanced HF.[3,19–22] An important consideration when planning HF PC is the presence of social determinants of health (eg, stability of housing, accessibility of fresh foods, availability of transportation) that may accelerate the progression of disease and affect PC goals and outcomes.[22] Specific to advanced HF management, areas applicable to PC conversations include shared decision-making and advance care planning in terms of HF therapies (eg, mechanical circulatory support [MCS], transplantation, and palliative inotropes) and treatment of refractory HF symptoms.[19,22]

Although underused, other forms of advanced CVD lend themselves well to the PC paradigm.[23] In severe coronary artery disease not amenable to revascularization and resistant to medical therapy, refractory angina can be debilitating, contributing to depression and anxiety and significantly affecting QOL.[23,24] Similarly, advanced peripheral artery disease is characterized by chronic pain, limited mobility, depression, social isolation, decreased QOL, and the potential for the development of chronic wounds and amputation.[23–25]

Cardiac arrhythmias, depending on type, may result in myriad symptoms, including fatigue, dyspnea, and activity intolerance, significantly affecting QOL.[23,24] Treatment of arrythmias may include multiple medications to reduce symptoms and implantable cardiac devices to prevent sudden cardiac death, which, in turn, may involve frequent and painful shocks and mental distress.[23] In severe valvular disease, symptoms are often problematic and significantly affect QOL and include dyspnea, fatigue, chest pain, palpitations, and dizziness.[23] Transcatheter aortic valve replacement has become an increasingly popular minimally invasive intervention to manage aortic stenosis symptoms yet maintains risk for other cardiac complications, including electrical conduction issues and the potential for pacemaker insertion.[26]

Although these forms of advanced CVD are often progressive, the clinical course tends to be undulating and sometimes unpredictable, frequently requiring urgent and complex medical decision-making and thus early and frequent PC involvement (not necessarily specialty) for symptom intervention, assessment of changing values, goals-of-care discussion, and advance care planning. This overall milieu maps clearly to the essential components of PC that guide symptom management, QOL, spiritual and psychological support, and bereavement support. Given that advanced CVD is ubiquitous (48.6% of Americans >20 years of age have some form of CVD)[1] and may be debilitating in later stages, it is not surprising that advanced CVD also represents the most common PC need, even ahead of cancer.[2] Models that support a scalable (ie, triggered) approach to PC in cancer are promising,[27] and individuals with advanced CVD such as HF may also benefit from this approach. Early PC discussions with the care team at crucial points of care could be based on the clinical course and decreases in QOL, providing a more scalable method to PC delivery and an opportunity to affect outcomes in individuals earlier in the advanced CVD trajectory.

PC DOMAINS AND ADVANCED CVD

PC in advanced CVD addresses 4 equally important yet intertwined domains: symptom management, QOL, spiritual and psychological support, and bereavement support (Figure 1).

Symptom Management

Symptom management is a major concern for individuals with advanced CVD. For example, individuals with advanced HF report more significant symptom burden and depression and lower spiritual well-being than those with advanced cancer.[28] For those with severe coronary artery disease, refractory angina substantially affects physical activity and social functioning.[29] Thus, meticulous integration of disease-based therapies is a critical component of symptom palliation because the underlying disease often drives symptoms and associated reductions in QOL. However, even with expert management, symptom relief for those with advanced CVD is rarely complete; symptoms frequently worsen with disease progression. PC approaches may temper refractory symptoms of dyspnea, pain, and fatigue through the prescription of opioids and nonpharmacological support such as cognitive behavioral therapy.[23] However, robust research on nonpharmacological interventions to help manage advanced CVD symptoms has been limited.[29,30]

Quality of Life

Improving QOL and reducing suffering for individuals with advanced CVD and their families are the primary goals of PC.[3,31] The symptom experience is a large factor in QOL across all advanced CVD trajectories, necessitating ongoing discussions about goals of care and individual priorities and treatment preferences. For those with HF, physical symptom burden is the strongest predictor of QOL.[28] Despite the scarcity of robust studies in other advanced CVD populations, symptom-related effects on mobility, physical functioning, socialization, and more likely influence QOL. Thus, the American Heart Association supports the use of palliative pharmacotherapy, including cardiovascular and palliative medicines that work collectively to control symptoms and to enhance QOL.[31] However, outside of HF, more rigorous research is needed to examine disease-related impacts on QOL in other advanced CVD populations.[23]

Spiritual and Psychological Support

PC involves a holistic approach that supports spiritual and psychological well-being to relieve the emotional, physical, social, and spiritual stressors associated with living with a chronic illness.[32] Spirituality is an important aspect of QOL and may aid the individual in coping with fluctuations and deteriorations throughout the advanced CVD trajectory.[33] Although limited mostly to advanced HF, PC interventions that include spiritual support have shown favorable improvements in QOL, care partner support, and some individual outcomes, including health care use and mortality.[34] PC interventions that provide psychological support have been tested more widely, largely in advanced coronary artery disease and HF,[35,36] with the inclusion of cognitive behavioral therapy, mindfulness, and motivational interviewing components showing promising results in reducing depression and anxiety and increasing QOL.[36] Although findings from spiritual and psychological support interventions in advanced coronary artery disease and HF are encouraging, interventional studies in other advanced CVD populations are needed.

Bereavement Support

Bereavement is a normal reaction to the loss of a loved one, accompanied by a period of sadness and grief that generally decreases over time.[37] Bereavement support is an integral part of PC, traditionally offered to care partners immediately after a person's death.[38] Studies show that care partner bereavement experiences are often complicated by emotional, familial, and financial challenges long after a person's death[39]; however, support is limited. A qualitative study of bereaved care partners found that only one-half received a follow-up contact at 3 to 6 weeks and one-fourth had a follow-up contact at 6 months.[40] To augment bereavement support, research suggests using a public health approach that emphasizes the capacity of community and social networks to support bereaved care partners.[41] Although several studies have found that a large number of bereaved care partners depend on family, friends, and neighbors as providers of bereavement support, there is a dearth of studies examining how health care systems can successfully build community capacity.[42] It is essential that PC services include strategies that leverage social and community networks to support the continuum of care partner bereavement care.

ADVANCED CVD SURGICAL APPROACHES AND PC

Mechanical Circulatory Support

MCS, including ventricular assist devices, represents a relatively infrequent but growing and high-intensity treatment option in advanced CVD that creates additional PC needs.[43] Recent national MCS program data show a 1-year survival rate of 86% and a 5-year survival rate of 64%. The average QOL significantly improves from before to after MCS and remains high over time, but the clinical course varies significantly and is poorly predicted by pre-MCS data.[44,45] New MCS-specific QOL measures have been developed and may be helpful to further understand this unique population.[46]

Care partners are invaluable care contributors for individuals living with MCS. However, the impact of providing care can result in worsening QOL and other psychological symptoms for care partners.[44] High levels of social support are associated with increased QOL among individuals with MCS, underscoring the importance of care partner involvement.[47] Most MCS programs require a care partner to be present for preimplantation and postimplantation training and to be available 24 hours daily for the first several weeks after implantation.[48] Care partners must adapt their routines and homes to support individuals living with MCS and manage batteries and other supplies.[49,50] Although most care partners are spouses, increased challenges are noted for nonspousal care partners and those who do not reside with the person living with MCS.[44,49]

Unique to the MCS population, the Centers for Medicare & Medicaid Services requires a PC team consultation before device implantation.[51] Analysis of these consultations has shown high variability and limited discussion of key MCS PC topics such as preparedness planning for device complications and failure and expectations for QOL after implantation.[52] Suggestions for structuring the consultations to improve their value include focusing on comfort, individual and family understanding of MCS therapy, goals of care, and spiritual care. Implementing these suggestions may enhance the value of the consultation and improve PC after implantation.[53]

Transplantation

Heart transplantation remains a principal treatment in many countries for select individuals with advanced HF, with the number of transplantations per year nearly doubling in the past decade.[54] There is a significant emotional, physical, and financial burden on the heart transplant recipient and their family while on the waiting list. These burdens are shared, and recommendations from professional organizations have been made to integrate specialty PC practitioners into the routine clinical care of individuals evaluated for heart transplantation in the preoperative, perioperative, and postoperative periods.[19] Despite a Joint Commission requirement for PC consultation before ventricular assist device implantation, the exact requirement is not mandatory for listing on the United Network for Organ Sharing wait list for heart transplantation, the primary registry for organ donation within the United States. Therefore, the role of the PC team and health care professionals in managing and supporting individuals awaiting transplantation remains center specific.

PC INTERVENTIONS AND OUTCOMES

PC interventions for individuals with advanced CVD are designed to meet the complex needs of the person and their family through effective communication, shared decision-making, incorporation of age-friendly principles, and advance care planning to address issues with symptom management, QOL, and care partner satisfaction.[7] Most PC interventions are multicomponent, holistic, and person and family centered, reflecting the 8 care domains of the National Consensus Project guidelines.[55] PC interventions primarily aim to improve QOL by addressing the physical, emotional, social, and spiritual challenges associated with the burden of advanced CVD and related care.[56,57] The content, design, and delivery of advanced CVD PC interventions vary, with most using a multidimensional approach focused on symptom management, psychosocial support, communication, and treatment decision-making (Figure 3).[3,56,58] Although high-quality PC clinical trials are growing slowly, robust intervention trials outside of HF remain scarce.[7,23]

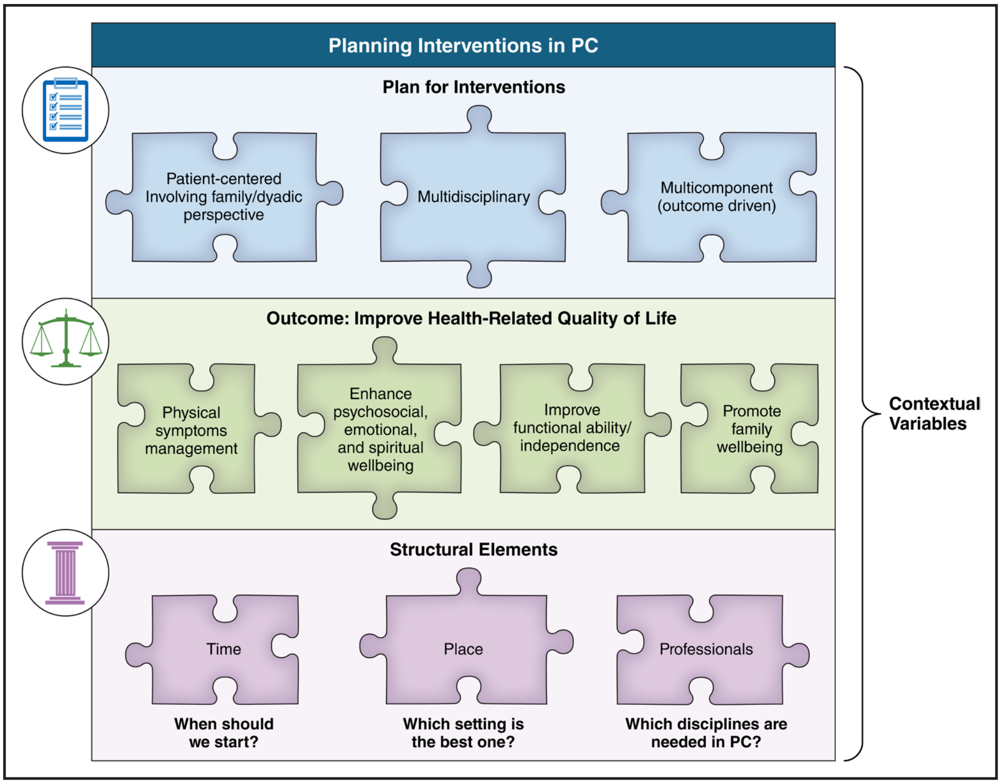


Figure 3. Planning interventions in PC.
The planning of palliative care (PC) interventions should involve considerable thought. We suggest that interventions be focused on the individual and include a family/dyadic perspective, a multidisciplinary approach, and multiple components. Intervention evaluation should focus on key quality-of-life outcomes in both the person with advanced CVD and the family. To achieve the best possible outcomes, careful consideration of the time and place for intervention should be made, as well as interdisciplinary involvement.

However, the involvement of disciplines new to PC interventions such as social workers,[59] and new contexts such as outpatient clinics[60] identifies the potential benefits of innovative interventions that integrate core PC principles while simultaneously proposing different scenarios for different moments of illness and contexts. This openness shows new perspectives for a broader spectrum of care, not limited to the end-of-life period. Because of a globally limited specialty-trained workforce, innovative models are needed that involve other disciplines with an expansion of PC to additional care settings so that we can adequately serve the needs of individuals with advanced CVD and their care partners to improve outcomes and to provide better care.[7]

Individuals With Advanced CVD

Despite the advent of new therapies and devices, advanced CVD–associated disability and poor QOL remain high.[61] People living with advanced CVD often report a significant burden of symptoms, psychological distress, and complex medical treatment decisions, which support the need for PC. Since 2015, randomized controlled trials have been performed, especially in adults with advanced HF because of its changing clinical trajectory, variations in symptoms and functional status, and profound uncertainty, requiring adaptive PC models.[7,23,56–62] Consistent with this view, recent studies have examined the impact of multidimensional PC interventions that aim to influence multiple outcomes on the person with advanced CVD and system sustainability (eg, symptom relief, medication management, psychological and spiritual support, QOL, anxiety, depression, and economic impact).[31,63,64]

Care Partners of Individuals With Advanced CVD

Care partners, often untrained and unpaid, are integral members of the care team and perform various tasks related to symptom monitoring, medication and nutrition management, emotional and social support, and health care–related communication.[65] Unlike caregiving in other serious diseases, advanced CVD caregiving hours may fluctuate significantly and be punctuated with periods of low need after medical optimization. Given their numerous tasks, care partners of individuals with advanced CVD need additional education, training, and support; however, few PC interventions are developed and tested for this population. In addition, there is a lack of consensus on what constitutes PC for care partners, an issue noted in prior reviews.[56] Most psychoeducational interventions with support or coaching elements aimed to improve care partner burden, QOL, and mental health. Although some demonstrated modest improvements in care partner burden/perception, nearly half of all studies did not improve care partner outcomes. It should be noted that a recent combined 12-week psychoeducation and exercise intervention study demonstrated improvement in physical function and care partner perception,[66] indicating that care partner focused (rather than person focused) may be a promising intervention area.

Dyads

Despite the crucial role of care partners, few studies have included a dyadic (person with advanced CVD/care partner) perspective. In this regard, studies have developed blended interventions to improve flexibility and to increase adherence to intervention components for both members of the person–care partner dyad. These include face-to-face PC consultations plus psychosocial and problem-solving support through telephone nurse-coach sessions[67,68] or even regular home visits provided by nurse case managers.[69] Primary outcomes are generally related to overall health, QOL, burden, and mood, as well as the use of health resources and satisfaction with care.[67–69] However, the body of knowledge available still lacks robust evidence to improve dyadic outcomes. Therefore, dyadic and community perspectives emerge as potentially essential research areas that are still grossly understudied.

DIVERSITY AND INCLUSION IN PC

For decades, PC has been shown to reduce morbidity, to improve physical and psychological symptoms, and to improve QOL in individuals with advanced CVD.[3] However, advancements in examining disparities in PC have been impeded by inadequate representation in research studies, limitations in studies focusing on health disparities, and the insufficiency of analytical methods in identifying the root causes of racial and ethnic differences. Furthermore, research on disparities in PC is constrained by mostly retrospective and observational studies conducted in inpatient settings.[70] These investigations are usually limited to a particular location and focus on medical facilities linked to metropolitan universities. The lack of established standards for categorizing, integrating, evaluating, and recording race and ethnicity in research makes addressing racial and ethnic disparities in PC even more challenging.[71]

For a more equitable health care system, personal needs must be prioritized, research must include many views, diverse cultures must be valued, and problem-solving methods must be used.[72] This will improve care team interactions, collaborative decision-making, and race- and ethnicity-related health care disparities. Early interventions, symptom-focused therapy, hospice, end-of-life care, and bereavement support are essential for equitable PC access.[73] Future studies must include inpatient, outpatient, academic, and community data in more extensive and diverse samples. Data aggregation and disaggregation are essential to understanding local and national fluctuations. It is critical to undertake a thorough analysis of use, quality, and outcomes from racial and ethnic populations when striving to enhance health care provision for individuals with advanced CVD.

The scientific community must also focus on prospective, longitudinal studies of racially and ethnically diverse individuals receiving PC. Conducting PC trials to create tailored interventions that address these differences is critical.[74] Furthermore, PC outcomes must be assessed in light of cultural differences while also considering the perspectives of individuals with advanced CVD and their families.[73] Last, future studies should investigate the impact of health care systems and care teams on care in racially and ethnically diverse populations, including aspects that influence PC provision such as the care setting, regional treatment intensity features, and health care policies and strategies.[73]

ETHICAL AND LEGAL CONSIDERATIONS IN PC AND IMPLANTED CARDIAC DEVICES

PC in advanced CVD is nuanced and multilayered, but it can become particularly complicated in the context of life-sustaining, implanted cardiac devices, including implantable cardioverter defibrillators (ICDs), pacemakers, and MCS devices. Clear communication, shared decision-making, advance care planning, age-friendly care, and multidisciplinary involvement are essential not only in device implantation but also in device deactivation (Figure 4).

Although legal and ethical precedents establish the permissibility of withholding and withdrawing life-sustaining therapies by a person with decision-making capacity,[75] cardiovascular practitioners and individuals with advanced CVD report ethical qualms concerning the deactivation of cardiovascular implantable electronic devices and MCS devices. Some equate deactivation to physician-assisted suicide/medical aid in dying.[76–78]

Devices have been distinguished from transplanted hearts[79] but also cardiopulmonary resuscitation, dialysis, and mechanical ventilation, partly because of their intracorporeal nature and the role of the devices (ie, in regulating or replacing cardiac functions).[79–81] A distinction also has been drawn between the deactivation of an ICD and the deactivation of a pacemaker in a person who is pacemaker dependent.[81–83] Pacemaker deactivation after ablation of the atrioventricular node in particular raises ethical complexities because the underlying electrical dysfunction is not the result of a disease process. Withdrawal of MCS also generates controversy, particularly about whether a person should be actively dying.[84,85]

These findings underscore the importance of clear communication in discussions about devices, ideally as part of the informed consent discussion at implantation. Advance care planning about deactivation should also take place as part of shared decision-making about device implantation. Revisitation of the goals of care after implantation may need to include an exploration of an individual's perceptions about their devices, particularly as perceptions may change over time, with age, across the disease trajectory, and with the development of multimobidity.[85] However, few discussions about deactivation occur before the end of life,[86] and many individuals, even

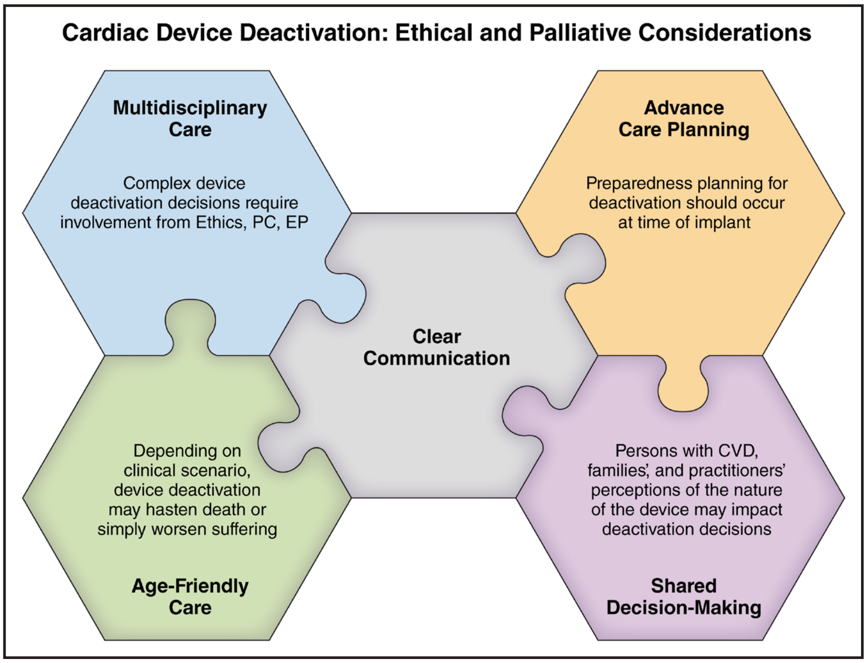


Figure 4. Cardiac device deactivation: ethical and palliative considerations. Clear communication is instrumental in guiding ethical and palliative care (PC) considerations and conversations that support interdisciplinary care, advance care planning, shared decision-making, and age-friendly care and reflect the desires for cardiac device deactivation of the person with advanced cardiovascular disease (CVD) and the family. EP indicates electrophysiology.

older individuals with do not attempt resuscitation orders, receive ICD shocks in their last days.[87,88]

Many hospitals and health systems have policies permitting "unilateral do not attempt resuscitation" or withdrawal of life-sustaining therapies without the consent of the person or surrogate. Although it appears rational to extend the unilateral withholding of external defibrillation to deactivation of an ICD (internal defibrillation), because the device is in a person's body, this act could be legally construed as battery and is not supported by most individuals with devices or by electrophysiology practitioners.[82–84]

Complexities in end-of-life device management argue for a multidisciplinary approach. Deactivation of the shocking function of an ICD may be theoretically consistent with do not attempt resuscitation orders and can prevent suffering associated with painful shocks as people die. Pacemaker deactivation, however, can lead to HF and other symptoms that worsen suffering at the end of life and may not hasten death. MCS withdrawal usually leads to rapid death, but the procedure of MCS withdrawal should take the effects of reduced circulation of palliative medications into consideration.[89] Careful consideration should be given to the underlying rhythm and cardiac function, as well as the nuances of device settings, often necessitating consultation with experts.

IMPLICATIONS AND FUTURE DIRECTIONS

Including PC principles across care settings and throughout the disease trajectory can significantly affect important PC domains such as symptom management, QOL, spiritual and psychological support, and bereavement support among individuals with advanced CVD and their care partners. Furthermore, multidimensional, interdisciplinary PC interventions deployed at various points across the disease continuum may improve outcomes. However, a lack of specially trained clinicians worldwide contributes to less than desired PC adoption rates in advanced CVD populations.

Although the body of evidence supporting PC in advanced CVD is growing, most trials remain in the HF domain, with more rigorous trials needed in other advanced CVD populations. Furthermore, conflicting evidence exists on the impact of PC interventions on care partners, and robust dyadic trials are lacking, necessitating future research. Similarly, little is known about the effects of PC across care settings and throughout the spectrum of advanced CVD, requiring increased measurement of outcomes to assess personal health status and care partner support, to identify PC needs, and to demonstrate PC effects.

In addition, providing culturally competent PC is vital as a result of changing demographics and advanced CVD rates, necessitating the active engagement of health care practitioners and stakeholders.[90] Depending on local health care systems, the reorganization of services to ensure that disenfranchised populations have equal access may be needed. Medical education reform, unconscious bias training, culturally sensitive health outcome indicators, and race- and ethnicity-neutral treatment recommendations can help to reduce health care disparities.[91] Most important, research is needed across care settings on personal values and perspectives among diverse cultures, ethnic groups, and geographic locations to inform tailored PC therapies and to increase uptake in under resourced populations.

The complexities of device deactivation also illustrate the need for clinical care models and research to explore best practices in end-of-life cardiac device management. This work must incorporate the perspectives of the person with advanced CVD and their care partner on device meaning. Moreover, PC services should strengthen the social and community networks during end-of-life care to support the care partner's bereavement trajectory because bereaved care partners often rely on their community and social networks for support.

CONCLUSIONS

PC for adults with advanced CVD is essential yet underused despite its potential to significantly improve the QOL for individuals living with advanced CVD and their care partners. Current evidence underscores the benefits of PC in managing symptoms, reducing psychological distress, and supporting both individuals with advanced CVD and their care partners. Future research should focus on robust clinical trials, especially for understudied advanced CVD populations, and outcomes to inform and enhance PC services. The ethical and legal complexities of managing life-sustaining cardiac devices necessitate clear guidelines and person-centered approaches to end-of-life care. Progressing PC for adults with advanced CVD requires a concerted effort to integrate comprehensive, person- and family-centered care models that address the multifaceted needs of this population to improve the QOL for people with advanced CVD and their care partners.

ARTICLE INFORMATION

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.

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Writing Group Disclosures

Writing group member	Employment	Research grant	Other research support	Speakers' bureau/ honoraria	Expert witness	Ownership interest	Consultant/ advisory board	Other
Lucinda J. Graven	Florida State University College of Nursing	Veterans Administration Office of Rural Health (CARE-HF Study)†	None	None	None	None	None	None
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Larry Allen	University of Colorado School of Medicine, Aurora	NIH (co-I)†; PCORI (PI)†	None	None	None	None	WCG ACI Clinical†; Boston Scientific*; Cytokinetics*; Novartis*; UpToDate*; Quidel†; American Heart Association*	None
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Lorraine S. Evangelista	UNLV School of Public Health	None	None	None	None	None	None	None
Amy Fiedler	University of California San Francisco	None	None	None	None	None	None	None
James Kirkpatrick	University of Washington	NIH-NIDDK (co-investigator with salary support on an ethics supplement to the KIND-HF trial. The supplement examines, in part, advance care planning in patients with kidney disease and ADHF)*	None	None	None	None	None	None
Lakeisha Mixon	University of Maryland Baltimore	None	None	None	None	None	Bayer U.S.*	None
Rachel Wells	University of Alabama at Birmingham	NIH (PI of a palliative care heart failure R00)*; Rita and Alex Hillman Foundation (co-PI of a serious illness pain pilot for adults with HF)*	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 $5000 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 $5000 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
Lynne T. Braun	Rush University Medical Center	None	None	None	None	None	None	None
Patricia M. Davidson	University of Wollongong (Australia)	None	None	None	None	None	None	None
Sarah Godfrey	UT Southwestern Medical Center	None	None	None	None	None	None	None
Tiny Jaarsma	Linköping University (Sweden)	EU (research grant)†	None	None	None	None	None	None
Daniel B. Kramer	Beth Israel Deaconess Medical Center	NIH (research grants)†	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 $5000 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 $5000 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.

†Significant.

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