TEN PRINCIPLES OF INTEGRATED PALLIATIVE AND SUPPORTIVE CARE IN HEART FAILURE

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Objective:
The learner will be able to describe ten principles of integrated palliative and supportive care for individuals and families living with HF based on the AAHFN SPC CoP position statement.

Background
Chronic heart failure (HF) is a burdensome health issue internationally, and in the United States (US) it affects more than 5 million Americans. Among Medicare beneficiaries, resource utilization in the last 6 months of life has increased by over 25% since 2000. This chronic and debilitating syndrome has high rates of morbidity and mortality. The complexity of management is increased due to comorbidities and the unique physical, psychological considerations in the elderly. In the US there are over 250,000 deaths annually attributable to HF. There is also an emerging body of evidence suggesting we are failing to adequately provide care at the end-of-life in chronic HF.

Despite the many interventions that help people live longer and improve QOL, including cardiac resynchronization therapy (CRT), left ventricular assist devices (LVAD) and internal cardiac defibrillators (ICDs) many individuals with HF still experience uncontrolled symptoms such as pain (41-78%), shortness of breath (60-88%), fatigue (69-82%), and depression (9-56%). Further, as many treatments and devices decrease the risk of sudden death, individuals live for longer periods with high symptom burden and uncertainty of prognosis.

Timely, HF-specific palliative care is now becoming widely recognized as an important part of promoting optimal outcomes for patients and their families. This is particularly important in the advanced stages of HF when specialists in palliative care can help alleviate distressing symptoms and promote timely decision-making. However, supportive and palliative approaches to care are recognized as appropriate at all phases of the HF trajectory, and they can be implemented by all providers who care for HF patients. Nurses are particularly well-positioned to provide supportive and palliative care to individuals and families facing the challenges and uncertainties of living with HF.

AAHFN Supportive and Palliative Care Community of Practice
The American Association of Heart Failure Nurses (AAHFN) is a specialty organization dedicated to advancing nursing education, clinical practice and research to improve HF patient outcomes. The AAHFN is a vehicle for sharing ideas, translating research findings into practice, promoting patient advocacy and setting priorities for the future to advance HF nursing. The mission of this organization is to unite professionals in the support and advancement of HF practice, education, and research to promote optimal patient outcomes.

In response to interest in palliative care among members and the increased endorsement of
palliative and supportive care in clinical HF guidelines, the AAHFN is sponsoring a Supportive and Palliative Care Community of Practice. As part of the establishment of this community, AAHFN has endorsed a position statement on supportive and palliative care in HF. This statement defines the essential elements of supportive and palliative care in HF, provides a vision for the future, and identifies the purpose of the Community of Practice.

The statement was developed by the Executive Committee of the AAHFN Supportive and Palliative Care Community of Practice (SPC CoP). This leadership team is composed of advanced practice nurses with expertise in HF and palliative care clinical practice, education, research and policy. The position statement draft was reviewed by seven experts from a variety of HF and palliative care backgrounds. Recommendations from these experts were incorporated into the final document which was then endorsed by the AAHFN Board of Directors.

**Position statement on supportive and palliative care in heart failure**
The number of people dying from chronic HF each year is increasing. Research has shown that many of these individuals suffer with physical, social and emotional distress and their families experience many challenges. Nurses have a long history of relieving suffering and have the knowledge, skills and competencies to care for patients and their families at the end-of-life. Currently, although we have documented many of the barriers to end-of-life care for patients with HF and their unmet needs, the solutions to these problems are not as apparent.

The AAHFN is well-poised to undertake a leadership role in advocating for advancements in health programs, clinical interventions and health services research to improve the care of individuals and families living with chronic HF. This is of particular importance as their needs increase towards the end-of-life. As healthcare professionals caring for these individuals we promote the following:

- Patient-centered, relationship-based, dignity-promoting healthcare for individuals and families living with heart failure.
- Openness, honesty and empathy in patient and family communication.
- Assessment and intervention appropriate to the diverse physical, cultural, social and emotional needs of the individual and their family.
- A focus on symptom management to decrease burden and promote quality of life.
- Advance care-planning at all stages along the heart failure continuum.
- Advocacy for the preferences of the patient and family at the end-of-life.
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- Evidence-based treatments and nationally-recognized guideline implementation in heart failure management, recognizing the vulnerabilities at the end-of-life.
- Research to improve clinical management.
- Health services research to develop and evaluate innovative models and processes of care that are appropriate in heart failure to advance education, clinical practice, health services, and healthcare policy.
- Collaboration to advocate for the needs of vulnerable individuals and their families.

As members of the American Association of Heart Failure Nurses, we aspire to partner with our patients and families from diagnosis to death. We endeavor to accompany them on their heart failure journey, be it medical management, mechanical circulatory support, transplant, palliative care or hospice, and to support their health-related decisions along the way. We strive to provide hope for relief of suffering and appropriate and compassionate care in advanced heart failure.

The AAHFN Supportive and Palliative Care Community of Practice will support you in working with patients and their families who are dealing with the challenges and complexities of this life-limiting illness. Join this group to contribute and stay informed about the latest supportive and palliative research and practices. For more information, request to join our community on Facebook at AAHFN Supportive and Palliative Care CoP or email Beth Fahlberg at beth.fahlberg@gmail.com.

Key principles of providing palliative care in heart failure

A palliative approach to the care of individuals with HF is fostered by the integration of ten key principles of palliative care in HF. These principles outlined in the position statement (see table 1) are described in detail below. These principles may be integrated into HF care by any healthcare professional, at any point following diagnosis, in any setting. The integration of these principles moves palliative care out of the realm of specialist palliative care and hospice, into the realm of chronic illness management. As described elsewhere, the intensity of supportive and palliative care provision increases as the needs of the patient and family increase, particularly as symptoms, functional limitations and psychosocial-spiritual needs increase with more compromised physiological status, either due to HF or due to other coexisting conditions.

Principle 1: Patient-centered, relationship-based, dignity-promoting healthcare for individuals and families living with heart failure.

Patients and families are the focus in palliative care. Patient-centered care strategies include making sure that patient priorities, unmet needs, preferences and available resources are used to determine the goals of care, the type, application and duration of interventions. The
family and caregivers are an integral part of providing palliative care, and should be included in accordance with the patient’s wishes, consent and cultural beliefs.

Promoting dignity is essential in achieving a palliative approach and chronically ill individual’s sense of dignity is often determined by how they are treated by their healthcare providers. We should recognize the people we care for as unique and important individuals and interact with them in a kind, compassionate and respectful manner. Paternalistic notions of patient “noncompliance” and “non-adherence” should be abandoned for a greater understanding of the patient experience, and incorporation of this understanding in our care for the individual. Understanding the patient experience includes assessment of the individual’s rationale for making decisions about his/her health and the challenges (s) he experiences in coping and adjusting with a chronic condition. This information and understanding of the individual and their family’s experiences should guide negotiation to develop a plan of care. This plan should include evidence-based interventions applied with clinical expertise and judgment in the context of the patient’s wishes and negotiated goals of treatment.

**Principle 2: Openness, honesty and empathy in patient and family communication.**
Communication is a critical foundation for providing palliative care, yet this element of care can be the most difficult for providers. Delivering bad news about prognosis or treatment options is one of the most challenging parts of providing palliative care, particularly when you have worked with a patient for some time, and you care about him/her. However, honest and open communication is often appreciated by patients and family, and is essential to building trust in the patient-provider relationship. In addition, it is important for providers to maintain the relationship with patient and family, even after the palliative care team and/or hospice has become involved in the care, so that they do not feel abandoned.

Information should be given in an empathetic manner, and should be appropriate to patient and family preferences for communication. The patient and family often know that something is wrong, or that (s)he is dying, yet they may be afraid to share their thoughts and fears with the provider, particularly if they know that by doing so, they may be faced with yet another round of hospitalizations, tests, procedures, and hard decisions. Delivery of bad news should occur in the context of hope and commitment to the patient-provider relationship. Messages should avoid terms such as “there’s nothing more we can do”, instead focusing on a commitment to help the individual live as (s)he wants to until the end, in comfort, with a good quality of life and with a sense that their dignity is still intact.

Some individuals, particularly in certain cultures, may not want information about their prognosis. These types of communication preferences should also be respected when possible, and alternate decision-makers should be appointed to receive this information and
make decisions consistent with the preferences of the individual.

**Principle 3: Assessment and intervention appropriate to the diverse physical, cultural, social and emotional needs of the individual and their family.**

A supportive and palliative philosophy is a holistic approach to care, considering not only the physical, but also the psychological, social and spiritual/ existential needs of the individual and family. While HF management often necessitates complex physiological management of symptoms, unmet psychosocial and spiritual needs may be the sources of greatest distress. Individuals physically limited by HF and other conditions may experience existential distress, such as a lack of meaning and purpose in life, which can cause them to feel that life is not worth living. Unmet psychosocial and spiritual needs such as feelings of being a burden to loved ones, depression and hopelessness are common triggers for thoughts of and attempts at suicide. Open-ended questions about what is most troubling to the individual can uncover sources of biopsychosocial-spiritual distress and potential strategies for intervention, and should be routinely included in patient care. Palliative and supportive care provision also recognizes the needs of the family for bereavement support after the patient’s death.

**Principle 4: A focus on symptom management to decrease burden and promote quality of life**

As the HF illness trajectory progresses, the focus of care often shifts from a curative approach to a greater focus on symptom management. Addressing burdensome symptoms such as dyspnea, fatigue and depression are critical in promoting health related quality of life and avoiding hospitalization. Information about the management of distressing symptoms in HF may be found elsewhere.

**Principle 5: Advance care-planning at all stages along the heart failure continuum.**

Discussions about prognosis and treatment preferences with the patient and family should begin early in the diagnosis with ongoing discussion at regular intervals or turning points. Individuals with HF may change their mind about preferences depending on the situation they are faced with, or their emotional state. Their decisions often change over the course of their illness, as they gain new experiences and adapt. Early in their diagnosis they may feel a particular situation would be unbearable, yet later they may accept it as an option when they have become accustomed to functional limitations and a more restricted lifestyle later in the HF trajectory.

**Principle 6: Advocacy for the preferences of the patient and family at the end-of-life.**

Treatment preferences of individuals with HF may be more complex than for people with cancer and other life-limiting illnesses. Most individuals with HF have lived with heart problems for many years, and have experienced numerous cardiac events, surgeries and procedures. Many have already had their lives extended through cardiopulmonary
resuscitation (CPR) and advanced cardiac life support. Many have implantable cardioverter defibrillators (ICDs) and pacemakers supporting their heart’s function, and preventing sudden cardiac death. The presence of these devices in their bodies is often a reminder that they almost died, but were successfully saved through complex cardiac interventions. These past experiences may play an important role in the decision-making processes of individuals and families with HF when faced with questions about their preferences for resuscitation and other life-saving and extending interventions. In addition, the widespread use of ICDs, LVADs and other implanted devices designed to extend life lead to some complex decisions and ethical dilemmas in advanced HF care. Organizations caring for individuals with these devices should have policies about how deactivation of the life-saving features of the devices at the end-of-life in accordance with documented patient and family preferences.

Principle 7: Evidence-based treatments and nationally-recognized guideline implementation in heart failure management, recognizing the vulnerabilities at the end-of-life.

Palliative care for individuals with HF begins with guideline-based HF management. Use and titration of HF medications, as described in the ACC/AHA guidelines, not only extends survival, it is also crucial to symptom management and promotion of QOL. Appropriate use of guideline-based therapy is therefore a critical piece of appropriate palliative care for individuals with HF.

In the advanced phase of HF (Stage D, NYHA Class III-IV), the primary goals of therapy are usually the promotion of comfort, functional status and QOL. At this point the individual with HF is often frail, with renal impairment, liver involvement, cachexia, and numerous comorbid conditions; therefore, they are at high risk of iatrogenic consequences associated with medications and procedures. The risks and benefits of any proposed medication changes, tests or procedures should be carefully weighed with the patient and family when making decisions. At this point medications often need to be adjusted and possibly withdrawn to maximize comfort, function and QOL. Fluid status of these individuals is often tenuous, with a high likelihood of frequent hospitalization for fluid overload.

Ongoing nurse case management is a key piece of palliative care for individuals with advanced HF and their families. Guideline-based care includes home weight and symptom monitoring, interventions to promote the appropriate use of medications, and the use of telehealth devices or other communication methods to provide ongoing monitoring and timely intervention for changes in the patient’s condition. Keys to appropriate palliative care provision in advanced HF include timely responses to questions and concerns, 24/7 availability and accurate communication about history, treatments, preferences and decisions between providers and across care settings.
Principle 8: Research to improve clinical management
Heart failure research has grown exponentially over the last two decades, with many studies examining interventions that promote survival, decrease hospitalization rates, and improve health-related quality of life. In addition, HF nursing research has made important contributions in numerous aspects of HF care including self-care and the recognition and treatment of depression. However, the palliative aspects of HF management, particularly in the field of advanced HF care, have received little attention. Advanced HF research has often been directed towards preserving life through such interventions as transplant, mechanical circulatory support and medications. However, little research has been done to improve symptom management and communication strategies in HF.

Palliative care research has become a field of growing importance, as evidenced by a recent symposium at the National Institutes of Health in August 2011, bringing together over 800 researchers interested in palliative and end-of-life care. At this important conference, many attendees identified HF and other chronic illnesses as important and understudied areas of palliative and end-of-life research. However, there are currently few palliative care researchers who also have expertise in HF care. HF researchers now have a tremendous opportunity to advance knowledge in this understudied yet critical area of HF care.

Palliative care HF research is needed to examine EOL experience in HF, and interventions that will promote comfort and QOL. Interventions need to be developed and tested that are specific to the unique physical, psychological, social and spiritual needs and perspectives of individuals with HF and their families. Research is also needed examining communication, advanced care planning and ongoing decision-making across the trajectory of HF.

Principle 9: Health services research to develop and evaluate innovative models and processes of care that are appropriate in heart failure to advance education, clinical practice, health services, and healthcare policy.
The reimbursement structure of the US healthcare system presents many challenges to providing palliative care for individuals with chronic illness, particularly when a “less than 6-month” prognosis, required for hospice referral, is not easily determined. While numerous prognostic models have been developed in an attempt to determine when hospice referral is appropriate, existing models remain limited in their accuracy, and the number of people with HF who die with little warning from cardiac or other acute events remains high. At the same time, reimbursement mechanisms are limited in the US that provide for outpatient interdisciplinary palliative and supportive care during the months or years people live with symptomatic HF, yet this type of care has been shown can reduce hospitalization rates and improve quality of life. As healthcare professionals, we need to advocate for policies and reimbursement structures that will promote palliative and supportive care for our patients and their families.
Principle 10: Collaboration to advocate for the needs of vulnerable individuals and their families.
Interdisciplinary team collaboration that bridges healthcare settings and specialties is a critical piece of providing palliative care to meet the complex needs of individuals and families living with advanced HF. The hospice model provides an excellent example of this type of collaboration, bringing together nurses, nursing assistants, physicians, social workers, counsellors, chaplains, volunteers and bereavement counsellors to meet the physical, psychological, social and spiritual needs of patients and families at the end-of-life. Earlier in the diagnosis, or when hospice is not desired or available, appropriate disciplines should be brought into the team to ensure that the needs of the whole person and their family are met. Collaboration with other healthcare professionals, such as through the AAHFN Supportive and Palliative Care Community of Practice, is critical in achieving this goal.

Conclusion
Increasingly as health professionals we are faced by increasing numbers of individuals ageing with HF. Current models of care commonly fail to provide the care and coordination required by this complex and devastating syndrome at the end-of-life. The members of the American Association of Heart Failure Nurses (AAHFN) are committed to implementing best practice principles to drive care reform for vulnerable individuals and their families at the end of life.
References


Table 1: Ten principles of an integrated approach to palliative care in heart failure

1. Patient-centered, relationship-based, dignity-promoting healthcare for individuals and families living with heart failure.

2. Openness, honesty and empathy in patient and family communication.

3. Assessment and intervention appropriate to the diverse physical, cultural, social and emotional needs of the individual and their family.

4. A focus on symptom management to decrease burden and promote quality of life.

5. Advance care-planning at all stages along the heart failure continuum.

6. Advocacy for the preferences of the patient and family at the end-of-life.

7. Evidence-based treatments and nationally-recognized guideline implementation in heart failure management, recognizing the vulnerabilities at the end-of-life.

8. Research to improve clinical management.

9. Health services research to develop and evaluate innovative models and processes of care that are appropriate in heart failure to advance education, clinical practice, health services, and healthcare policy.

10. Collaboration to advocate for the needs of vulnerable individuals and their families.