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Designing and Testing an End-of-Life Discussion Intervention for African American Patients With Heart Failure and Their Families

Ubolrat Piamjariyakul, PhD, RN,

Research associate professor, School of Nursing, University of Kansas Medical Center

Carol E. Smith, PhD, RN, FAAN,

Professor, School of Nursing and Preventive Medicine & Public Health, University of Kansas Medical Center

Marilyn Werkowitch, BSN, RN,

Research assistant, School of Nursing, University of Kansas Medical Center

Noreen Thompson, MSN, RN,

Psychiatric nurse specialist, Department of Nursing Clinical Excellence, University of Kansas Medical Center

Maria Fox, DNP, APRN-CNS, ACHPN, CCRN,

Director, Advanced Practice Professionals, University of Kansas Health System

Karin Porter Williamson, MD, FAAHPM, and

Associate professor and senior scientist, Palliative Medicine, University of Kansas Medical Center

Lori Olson, MD

Assistant professor and senior scientist, Internal Medicine, University of Kansas Medical Center

Abstract

There is an escalating prevalence of heart failure (HF) with high mortality. Compared with other races, African Americans face a higher incidence of HF at earlier age of onset, with more rapid progression, and with increased family care burden and greater care costs and disparity in health care services at the end of life (EOL). Concomitant out-of-pocket HF costs and care demands indicate the need for early discussion of palliative and EOL care needs. We therefore developed and pilot tested a culturally sensitive intervention specific to the needs of African American HF patients and their families at the EOL. Our pilot study findings encompass patient and caregiver perspectives and align with the state of EOL science. The ultimate long-term goal of this intervention strategy is to translate into practice the preferred, culturally sensitive, and most cost-efficient EOL care recommendations for HF patients and families.

Address correspondence to Ubolrat Piamjariyakul, PhD, RN, West Virginia University, School of Nursing, Health Sciences Center, Post Office Box 9600 - Office 6414A, Morgantown, WV 26506-9602 (upiamjariyakul@kumc.edu).

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Keywords

culturally sensitive intervention; end-stage HF; palliative and end-of-life care discussion

Heart failure (HF) affects approximately 8 million Americans and is expected to have a 46% increase in prevalence from 2012 to 2030.¹ There are 915 000 new cases of HF each year, with an annual national US cost of \$30.7 billion.² Most HF patients die within 10 years of first diagnosis, and there is an escalating prevalence of HF with high mortality (20% in 1 year, 59% in 5 years, 99% in 10 years).¹ Notably, the 5-year mortality rate is higher among African American men (52% vs 41%; $P = .02$) and women (46% vs 36%; $P = .03$) compared with white patients with HF.³ Compared with other races, African Americans face a higher incidence of HF at earlier age of onset, with more rapid progression and with increased family care burden and greater care costs and disparity in health care services at the end of life (EOL).¹ Concomitant out-of-pocket costs and HF families' care demands indicate the need for early discussion of palliative and EOL care needs.⁴ Notably, millions of dollars are spent annually on HF acute care during the last 6 to 12 months of the patients' lives.⁵

Care Options at the EOL

A study conducted by The Dartmouth Institute for Health Policy and Clinical Practice found that patients with chronic illnesses in their last 2 years of life accounted for 25% of total Medicare spending, much of it paying for repeated hospitalizations.⁶ Early discussion of goals and preferences for treatment as the illness progresses is essential, as researchers in the controlled trial (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments) found it was difficult or impossible for hospitalized patients to change health care requests in the few days before death.⁷ These early discussions can result in care with dignity by reducing repeat hospitalizations and with greater use of hospice and home EOL services.⁶

Our long-term multidisciplinary research team has been testing culturally sensitive interventions and disseminating study results on African American families managing complex HF home care.^{8–11} The results from HF patients, their family members, and multidisciplinary HF professionals in our focus groups indicated critical needs for family discussions of EOL care options.¹² Little is known about the impact of palliative consultation on outcomes for minority patients. However, it is known that EOL care for those with HF must encompass specific challenges of this disease. Given the escalating incidence, mortality, and devastating effects of end-stage HF, providing patients and their family members with EOL information could potentially increase their confidence and management skills in home EOL care and decrease their care burden. Thus, it is imperative to develop interventions that address specific HF EOL care that is also culturally sensitive to African Americans' needs.

Purpose

The purpose of this article is to describe our development and pilot testing of a culturally sensitive HF EOL coaching intervention. This intervention is based on the synthesis of the

literature and our multidisciplinary research team's past pilot study results to address EOL care for end-stage HF patients that aligns with the preferences of patients and their family members.^{11,12}

SYNTHESIS OF THE LITERATURE AND PRELIMINARY STUDIES

End-Stage HF Trajectory and Specific HF Care Needs at the EOL

End-stage HF refers to an HF condition that has progressed to a point where traditional treatments and symptom management are no longer effective (ie, symptoms even at rest).¹³ At end-stage HF, patients and their family members need HF-specific palliative care (defined as relief from symptoms during serious illness). Fifty percent of all deaths annually in the United States occur in the hospital.¹⁴ However, studies report that at the EOL, people would prefer not to be in the hospital, not to be in pain or discomfort, not to be a burden on loved ones, not to be sustained artificially, and to have religious prayer or pastoral care.⁶ To succeed in delivering care concordant with these preferences, patients and families need a better understanding of their illness progression over time and the meaning of related treatment options. As a family, they need to have time to explore and discuss important beliefs and values within this context with their health care providers. National organizations have recognized the importance of this shared decision making in the HF population, yet little research has been tested on how this can be successfully implemented in practice.¹⁵ Our intervention starts the conversation for meeting these needs.

Understanding the common HF illness trajectory will help health care providers, patients, and families identify specific HF care needs.¹⁴ As shown in the Figure, the trajectory depicts typical HF decline and can indicate when conversations with families about EOL care options should be initiated. The trajectory curves are based on the patient's clinical, functional, and psychosocial measures, such as depression,¹⁶ known to precede HF rehospitalizations and death.

Family out-of-pocket costs of care are also shown to climb as the repeated hospitalizations and other HF-related nonreimbursed costs escalate.⁴ Each patient's out-of-pocket HF health care cost curve allows for the identification of the family's cost burden and needs for social services referral. This type of graph is a powerful visual tool to help the HF population with low health literacy and the inability to read or fully understand health information. Health literacy is a major barrier to chronic illness care and is associated with poor EOL outcomes.¹⁷

Individuals with HF have a low prevalence of completing advance care planning.¹⁸ In particular, our literature review found that very few African American families discuss HF-related EOL care options before end-stage HF hospitalizations occur. This results in unwanted care, high health care costs, and family out-of-pocket expenses.^{4,19} The overwhelming number of patients do not want extraordinary futile care,²⁰ yet most African American patients do not have an advance directive, professional guidance, or discussions of EOL options specific to HF decline.^{11,12,21}

Specific HF Symptoms at the EOL

Specific care is needed for the unique end-stage HF-related symptoms such as refractory dyspnea, depression, anxiety, fatigue, abdominal bloating, lower extremity edema, pain, insomnia, weakness, arrhythmias, and cognitive impairment.¹³ The management of these symptoms is often a combination of guideline-directed medical therapy and supportive care. Discussions with families, physicians, and nurses regarding the patient and family goals of care and values surrounding implantable cardiac devices; intravenous therapy such as palliative inotrope infusions or diuretics; and increasing medicalization are necessary to create a patient-centered plan of care. Conversations surrounding the management of existing implanted cardiac devices such as internal defibrillators are also essential in discussing avoidance of potential suffering at the EOL.²² Careful assessment and management of depression and anxiety in a setting of often decreased functional status and social isolation must be addressed as well as practical support of additional stressors, including financial worries that are commonplace in end-stage HF.¹⁶ The management of specific HF symptoms should be aligned with national guidelines.¹³ Early discussions of the sensitive topics of treatment preferences and EOL options reassure patients and their families that providers are engaged in identifying and honoring what matters most, and they also provide rapport and trust when an individual's clinical condition changes.²³

Recommendations for HF Care at the EOL

The most common recommendation for EOL support is to use hospice care. However, there can be conflicting views among African Americans regarding use of hospice or even considering any EOL care other than relying on faith first and foremost.²⁰ Most African Americans indicate that they want family care when dying at home. Furthermore, African Americans may lack insurance coverage for hospice or home care, and they are often doubtful about nursing homes or hospice and do not understand the Hospice Medicare Benefit.²¹ Therefore, it is important for them to understand that hospice care at home supports families who play a major role in the patient's EOL care and in any decision making.¹² Some studies, but not all, have found the use of hospice care is accompanied by a decrease in the cost to families for EOL home care.⁵

There are challenges in providing hospice care for end-stage HF patients. It is imperative that the HF and hospice clinicians work together to provide symptomatic management specific for end-stage HF patients, which often differs from the needs of individuals with underlying terminal illnesses more common to the hospice providers, such as cancer. Increasingly, medically complex therapies that often provide symptomatic improvement blur the line between aggressive and comfort measures and challenge traditional viewpoints of hospice care.²⁴ As the trajectory dips illustrate, HF patients have dramatic worsening of their end-stage HF but then months of stability because of medications or systemic fluid reduction, resulting in discharge from hospice. National reports from HF experts reveal that 38% to 58% of HF patients recover sufficiently to be discharged from hospice, yet all return to a downward illness trajectory.¹⁴ Families must be prepared to manage this situation, and professionals must discuss this possibility with patients, their families, and HF providers. Furthermore, the family's cultural background must be considered.

Designing a Culturally Sensitive Intervention for African Americans With End-Stage HF

African American families are described as tightly knit and extended and include many close friends they consider related. A strong expectation is that family members care for loved ones in their own homes. This choice is always preferred to someone coming “from the outside.”²¹ Therefore, this strong family foundation can be used to begin a discussion of EOL issues.²⁵ Overall, 80% of African Americans consider themselves to be religious and to always seek spiritual guidance. A survey of African Americans revealed that 70% attend religious services at least a few times a month, 80% pray nearly every day, 27% read religious books, and 21% watch or listen to religious programming on television or radio daily.²¹

Culturally sensitive factors commonly associated with African Americans should be verified with each family and considered when discussing EOL care options. These factors include (1) lack of knowledge about the options available at EOL; (2) rare use of hospice care; (3) the concept of suffering as an accepted part of life and death; (4) that EOL should be managed through religious practices; and (5) distrust of health care organizations. Such factors or beliefs have led to seeking life-prolonging measures even when these are associated with greater distress.²¹ Furthermore, nonacceptance of an advance directive and a do-not-resuscitate order among African Americans appears to be part of a much broader pattern of values regarding quality of life. This perspective may stem from a long history of distrust of the white-dominated health care system.²¹ Understanding these family and culturally sensitive factors led our research team to select a coaching approach for intervening with African American families for EOL care.

In this intervention, coaching by health professionals is a process in which the nurse engages the patient and family in strategies for end-stage HF and EOL symptom management.²⁶ Our coaching interventions for EOL care are built on evidence-based national clinical guidelines.^{21,27} Cultural sensitivity is defined as “the knowledge and interpersonal skills that allow providers to understand, appreciate, and work with individuals from cultures other than their own.” It involves an “awareness and acceptance of cultural differences.”²⁸ Our coaching framework was used to design our culturally sensitive EOL care intervention for African American HF patients and their families. The framework is a comprehensive system-based model described in a previous *Heart & Lung* article testing HF home care interventions.¹⁰

Our previous studies tested the culturally sensitive coaching intervention incorporating EOL preferences of HF patients and family members.^{9,12} These studies identified the success of our coaching approaches, which were highly rated.¹⁰ The coaching method was also well received in our pilot study, using culturally sensitive approaches with the African American families.¹¹ In these studies, both patient HF rehospitalizations and caregiver home care burden were significantly reduced compared with control families. Thus, our coaching framework and intervention can be a powerful method to identify and address the specific needs of end-stage HF patients and family members.

Results From Testing Our EOL Intervention

Overall, our past study results indicate that patients and family members would be receptive to EOL care information. Specifically, in 1 study, the 2-way analysis of variance was conducted to examine the effect of race (African American vs white) and treatment group (nurse-led HF coaching discussion about HF vs standard care) on the change in depression scores from baseline to 6 months postintervention.²⁹ The Levene test indicated homogeneity of variance between groups. There was a significant interaction between the effects of race and treatment group on the change in depression scores ($F_{1, 151} = 4.68, P = .032$). Furthermore, Fisher Lease Significant Difference post hoc analysis found a decrease in depression in all HF patients compared with controls. And, notably, there was a significantly greater decrease in depression scores among African American versus white patients in the intervention group (mean difference, 3.2; $P < .05$). Thus, coaching methods helped patients and families manage their depression, indicating that African American patients greatly benefit from nurse-led coaching discussions.

In our focus group research, coaching techniques helped patients share emotions and needs with their family members and friends. For example, in our pilot HF home care study with African Americans, 80% of participants stated that they had not discussed patients' EOL care planning.¹¹ Examples of responses were the following: "I don't know exactly about doing any forms [i.e., advance directives]" and "We don't have any legal documents...."(p470) Our first assessment of African American EOL preferences used sensitive open-ended questions to develop rapport and begin to elicit a family's knowledge about EOL care. The EOL themes found across all subjects included their high regard for family involvement in EOL care, pain control, dying at home, not wanting to prolong the dying process, and having professionals involved in the discussions about HF EOL treatment and support options.¹² These themes are aligned with literature addressing the cultural challenges among African Americans.²⁵

OUR CULTURALLY SENSITIVE HF EOL COACHING INTERVENTION

In our intervention tested with African Americans, each 2-hour EOL coaching session included information about HF management related to an individual family's strengths and challenges.^{8,9,11} For example, African Americans have multiple family caregivers who want to help; discussing how to delegate the multitude of tasks in EOL care can assist them to share the workload and reduce fatigue for the primary caregiver. Thus, the nurse/coach helps the family coordinate arrangements for transportation, grocery shopping, housekeeping, supportive telephone contacts, and keeping up-to-date on medical care (appointments, lab draws, etc). The coach also engages local church-based lay parish nurses (who are highly accepted in this community) to support families in HF EOL home care management. Having other African Americans who have become comfortable with these discussion topics sit in on the session may be helpful. Applications for reduced-cost drug programs³⁰ to assist the family with out-of-pocket home HF care expenses can be introduced. A summary of our nurse guide for end-of-life discussion and coaching intervention implementation is presented in the Table.

The trajectory graph (Figure), the “Conversation Ready” pamphlet,³¹ and advance care planning are the tools given to help the patient and family members to think through what matters most to them and what their goals of EOL care are. These are the essential elements of discussion for patients and family to contemplate. Their use of and acceptance of different EOL support services are directly related to their selected EOL treatment—there must be good communication about their treatment and the services selected to provide the care they desire.

Using the “Conversation Ready” pamphlet, along with the HF end-stage trajectory graph, the nurse interventionist (1) describes options for EOL care when the patient’s HF condition becomes end-stage; (2) encourages the patient and family to make decisions about HF care options based on their preferences; (3) helps them with the advance directive forms and the Durable Power of Attorney for Health Care and, when signed, sees that these are filed in the medical record and provides copies for families to keep; and (5) assists families with ways to communicate EOL decisions to friends, clergy, and health care professionals.

During the coaching sessions, the family members are given (1) a graph showing the typical end-stage HF trajectory to assist them in understanding the HF decline, (2) specific information on HF symptoms at EOL such as breathlessness and comorbid symptom recognition, (3) information as to when to telephone physicians or hospice nurses, (4) resources for telephone contact for religious support, and (5) ways to identify and care for depression. Screening patients for depression to distinguish between grief responses is essential. It is well known that depression can have a major negative effect during HF decline.¹⁶ Thus, the coaching intervention guides patient and family discussions of preferences for specific HF EOL care options, advanced directive completion, and provide resources they may use. The nurse interventionist also helps the patient and family members write down questions for physicians and practice communicating their preferences to the health care providers.

As an exemplar model for communicating patients’ EOL wishes, a palliative physician (1 of the coauthors) at our University Medical Center established the Transportable Physician Orders for Patient Preferences (TPOPP) 2-page form. The TPOPP form allows placing each patient’s preferences into actionable medical orders documented in a universal and transferable format. This format is within the Physician Orders for Life Sustaining Treatments paradigm of programs, a growing approach across the United States.³² The key objective of our TPOPP program is to provide patients with forms they can travel with and give to new health care providers. Our University Medical Center is 1 of 8 hospitals in the Midwest metropolitan area committed to implementing TPOPP across interdisciplinary health care professionals.

Also, during the EOL coaching session, each patient and family member will be asked to “teach-back” or tell the nurse what was learned in the discussion. This teach-back method is used throughout the discussion to clarify any misunderstanding and to identify the resources needed by the family. This method is another powerful tool for discussing this sensitive topic and advocating for family input. This approach works well among elderly populations and African Americans, who may be reluctant to ask questions.²¹ In a previous pilot study with

African Americans, our teach-back data indicated that the participants gained a 45% improvement in HF knowledge, symptom monitoring, and symptom reporting. These data were measured by tabulating the topics that needed reinforcement, which were noted in the teach-back checklist. Also, 90% of participants rated our coaching information as “helpful” in solving HF home care challenges.

Procedures for Intervention Implementation

The foremost procedure for success is thorough training and support of nurses who will undertake these sensitive discussions. The nationally available material “Conversation Ready,” supported by the Institute for Healthcare Improvement, can be used for this training. These materials are essential guides that provide tools for patients to communicate their wishes and preferences for EOL care options,³¹ along with other key strategies for implementing our EOL intervention. It is important to develop a rapport with all patients before discussing EOL options and specifically with African American families due to their reluctance to discuss or complete the legal forms for EOL care.^{21,31} The nurse interventionist must also plan for at least a 2-hour coaching session, which allows time for pauses, questions, teach-back, and emotional consideration of this grave and sensitive topic. During this discussion, it is important to use calm words and nonmedical language instead of such terminology as *advance directives*, *opioids*, *hydration for comfort and limited nutrition*, or *palliative sedation*. It is recommended that the term *comfort care* be used in the initial discussion; however, when simplifying the language, the nurse should be careful not to patronize.³¹

Following any discussion about EOL care, most families want time to read and think through the advance directive form. Families may also request more sessions to be scheduled at their convenience. Options for managing patient’s discharges and readmissions to hospice care are discussed, and care options that are derived from interdisciplinary teams of HF and EOL palliative health care experts are offered that align with patient preferences. Thus, the initial coaching session with the patient and family on EOL care should be followed by telephone calls to answer any questions they may have. Allowing flexible time for the intervention discussions and showing a willingness to reschedule are essential.

All care options included in our intervention are aligned with national guidelines for Decisions on Life Sustaining Treatment and EOL Care.³³ These options were conveyed by the experienced nurse interventionist in our previous studies, including the explanation to families about the potential revocation of hospice during periodic temporary improvement as occurs in end-stage HF.¹⁵ Our past data indicate that Class III or IV HF patients would need an average of 3 EOL sessions across the last year of life.^{5,6}

DISCUSSION

Our EOL intervention addresses the health care national priorities established for improving quality of care for racial and ethnic minorities with palliative and EOL care needs.^{15,34} Our intervention can impact the escalating populations of HF patients by providing disease-specific and timely palliative education and support options to manage complex end-stage

HF symptoms. Such options can reduce family out-of-pocket and health care cost burdens while providing preferred patient care.

Although African American families have strong traditions of greater numbers of family members, they are shown to be less prepared for EOL home care compared with other races or ethnic groups.²¹ Our multiperspective intervention reflects culturally sensitive preferences from patients for palliative and EOL care. It is imperative that these preferences be identified by African American patients for end-stage HF.

Research has found that the regional costs of chronic care at Gundersen/Mayo Clinics were lower than the national average because of their success in increasing the number of patients and families who signed advance directives with most of patient preferences for dying at home.⁶ According to the Dartmouth study in 2013, the University of Kansas Hospital had the largest absolute drop in the number of patients dying in the hospital (–13.4 percentage points) versus their preferred wishes to die at home or in hospice care.⁶ This reduction in in-hospital deaths and the increase in patients who preferred dying at home are positive outcomes of EOL discussions, as is the increase in requests from HF patients and their family members for early planning and access to palliative care.^{6,19}

Our University Medical Center initiative for improving HF EOL care includes patient and family engagement and interdisciplinary approaches among home care and hospice experts.^{35,36} Training professionals to discuss EOL needs with the patient and family based on the clinical status and their preferences can result in tailoring palliative and EOL care to each individual's wishes.³⁵ Formiga found that 64% of family members requested discussion of HF treatment choices, and almost all wanted more information about EOL care.³⁷ Most family members request discussions with physicians about HF treatment choices, and almost all wanted more information about EOL care.

In future studies, we plan to collect data about the use of this intervention. Professionals using our coaching-based intervention plan for HF EOL discussions with African American patients will be asked to evaluate its helpfulness, cultural sensitivity, patient and family member responses, and use of the HF care options.⁹ Professionals will also be asked to complete the Duke Diffusion of Innovations battery, which measures ease of implementing and satisfaction with the intervention and its potential for long-term use.³⁸ Also, we will test patient and family member health outcomes (ie, care burden, health services costs, and quality of life) in more detail.

CONCLUSION

The synthesis of literature and our previous pilot study findings reflect the state of EOL science as well as patient, professional, and caregiver perspectives. The ultimate long-term goal of this intervention strategy is to translate into practice the preferred, culturally sensitive, and most cost-efficient EOL care recommendations for HF patients and families. Furthermore, we wish to support professionals with information and guides for having these sensitive conversations.

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FIGURE.

Trajectory of HF with prompts for palliative and EOL care discussions. This graph is based on hospitalization frequency across the last 5 years of end-stage HF patients. The solid lower black line represents a patient's HF clinical status trajectory with the typical episodic downward "dips" before HF-related rehospitalizations. These dips are often preceded by the upward waves of increased depression and increased family home care burden (dashed line). The overarching thick top line is the ever-increasing family out-of-pocket costs aligned with the increasing frequency of hospitalizations across 5 years that culminate at the vertical dashed line on the right (before death). The F slopes derived from all these trajectory lines can be used to predict HF declines. The vertical dashed lines capture when prompts for palliative and EOL care discussions with patients and their family members are best repeated. EOL indicates end of life; HF heart failure.

TABLE

Nurse Guide for EOL Discussion and Coaching Intervention Implementation

Objectives	Intervention Activities
<i>Use these evidence-based coaching and teach-back strategies for achieving EOL session objectives.</i>	<i>Nurse allows approximately 2 hours for initial session. Coaching and teach-back strategies will be used throughout.</i>
<p>1. Focus on Conversation Ready in advance care planning for HF patients and their families to discuss.</p> <ul style="list-style-type: none"> Begin by asking patient/family to tell you what they know about HF and care for end-stage HF. Explore patient/family's understanding of palliative care or hospice in the context of end-stage HF. 	<p>Begins with Conversation Ready approaches. The research nurse will introduce the subject of "Advanced Health Care Planning" for EOL care in a sensitive manner. Nurse uses open-ended questions to explore patient/family understanding of end-stage HF care: "Tell me about what you understand is going on with your [loved one] in [their] heart failure illness?" "What do you know about [palliative care] or [hospice] and how those services can help someone like your [loved one] with symptom management and care when your [loved one] becomes sicker." "We want to understand what your family and your [loved one's] wishes are in regard to [their] care when they get sicker so that we can (1) honor those wishes and (2) make sure that you and other family members have enough information about HF to meet your needs."</p>
2. Use the trajectory of typical advanced HF illness graph as a way to grasp what is typical in end-stage HF at EOL.	Seeing the illness trajectory, patients with advanced HF can anticipate exacerbations (ie, breathlessness, risk of falling, anxiety, and other associated symptoms with HF). Emphasize the specific and progressive HF decline and deteriorating functioning that occurs over time and that there are options for planning for the inevitable.
3. Discuss EOL care choices. Patient/family members will report and discuss any topics that make them uncomfortable and their concerns about home EOL care choices.	EOL care choices: (1) Palliative home health care and (2) hospice care in home setting versus nursing home/long-term care setting. (This depends on what the family is able to provide in terms of care. Many times, families cannot stay home because of work, and then a nursing home may be the choice.) Discuss why it is important to have a conversation about treatments and interventions before the need arises.
4. Discuss HF advance care planning components. <ul style="list-style-type: none"> Patients and family members will successfully identify the components of advance care planning. 	What is advance care planning and why is it important? During these discussions, the nurse will review The Heart Failure Society of America Advance Care Planning Module and The Center for Practical Bioethics Caring Conversations workbook. Introduction of HF advance care planning components. (1) Advance directive, (2) TPOPP form, and (3) Durable Power of Attorney for Health Care. The nurse will encourage completion of forms and offer assistance for disseminating the forms to primary care physicians and other family members and having their EOL decision form visible at the person's bedside and/or on the refrigerator at home.
5. Identify resources for palliative care options based on family's preferences. <ul style="list-style-type: none"> Patient/family (only if they request) will successfully prepare advance care planning documents with assistance of the nurse using the resources provided. 	Nurse will describe social worker referral and discuss resource programs (medication and low-sodium food and cost assistance) to help patients and family caregivers managing home EOL care. Discuss how to avoid stress, manage fatigue, and coordinate home care among available family caregivers. Describe pastoral/chaplain support and parish or church nurse availability.

Abbreviations: EOL, end of life; HF, heart failure; TPOPP, Transportable Physician Orders for Patient Preferences.