Chronic heart failure (HF) is a growing public health concern in Western nations. Incidence of HF increases with age, and demographics in the United States support a growing HF population. Annually, more than 100,000 people are admitted to hospitals because of HF. Patients with chronic HF experience a highly morbid and life-limiting illness while suffering from substantial physical and psychosocial burdens. What is the state of the science regarding the use of palliative care for community-dwelling adult patients with HF? A review of the scientific literature was conducted using the key words “palliative care” and “heart failure” in several electronic databases (CINAHL, Medline, Proquest) from October 15 to November 15, 2011. Eleven of the 16 articles found indicated that palliative care is underused by HF patients. There is a large unmet care need for adults with chronic HF and their family caregivers. Home healthcare professionals develop and maintain relationships with community-dwelling patients with chronic HF over the course of their HF illness trajectory. Home healthcare professionals are in a unique position to identify HF patients who may benefit from palliative care programs delivered across care settings in the community. By developing ongoing relationships with patients and their family caregivers, we are able to focus on the complete care needs of this patient population and assist them with advanced care planning, psychological and social issues, and symptom management. We can also improve communication among care providers and patients/families to identify goals of care along the trajectory of HF illness.
Case Study
William Blake is a 70-year-old white male with a history of multiple hospital admissions due to a 3-year history of heart failure (HF). When visited by his visiting nurse (VN) one day, he presented with increased shortness of breath (SOB) on exertion and anxiety, compared to his status on the previous home visit. Mr. Blake informed the nurse that he has been unable to get any or much sleep during the last week and he has been keeping his wife up all night who is exhausted. Mr. Blake wakes up often during the night with frequent, dry cough and his wife has been assisting him with bathing and dressing due to fatigue and weakness. After further discussion, he casually mentions that his shoes and his pants feel tight, but he blames this on the recent holidays and related overeating. On examination, the VN finds Mr. Blake has distended jugular veins, +3 pitting edema in his lower extremities, and a 5-pound weight gain since last week.

The VN reinforces previous education about managing HF at home: reviewing with Mr. and Mrs. Blake his diet, the importance of daily weights, and his medication regimen. Because of the relationship the VN has established with this couple and because she understands that their quality of life is being affected by these troubling symptoms, the VN introduces the possible benefits to be derived from palliative care (PC) services. After discussion with Mr. and Mrs. Blake, an agreement was reached to contact the primary care provider to discuss a referral to the PC team. The VN explains that PC services focus on maximizing quality of life, identifying goals of care, and providing comfort and relief of pain and other distressing symptoms for patients with serious and complex illness (Meier et al., 2010).

The VN was able to teach the Blakes how to monitor and report his daily weight, how to monitor his blood pressure, and gave instructions about when to call the VN or the primary care provider. The social worker also was called in and was able to work with the Blakes to provide counseling about community resources and support. The nutritionist worked with Mrs. Blake (who was the cook in the family) to understand dietary changes including ways to change Mr. Blake’s favorite meals to meet dietary requirements. The physical therapist and occupational therapist were able to work with Mr. Blake to assist him with activities of daily living and safety with ambulation and transfers balancing energy and fatigue.

Search Strategy
This article will address the question of how PC can best be offered to older adult patients living at home with HF. One must first investigate the evidence base supporting the use of PC for older adult patients diagnosed with HF. To investigate this question, a review of the scientific literature was conducted using keywords “palliative care,” “heart failure,” and “home care” in several electronic databases (CINAHL, Medline, Proquest) from October 15, 2011, to November 15, 2011. Only full-text English research articles from the last 5 years (2007–2011) were selected for review. Sixteen (16) articles were reviewed and integrated into this analysis of the literature, with the goal of providing home care clinicians with an update about what is known in this area.

HF
HF is a condition in which the heart cannot pump enough blood to meet the body’s needs. HF develops over time as the heart’s pumping action grows weaker. The condition can affect the right side of the heart only, or it can affect both sides of the heart. Most cases involve both sides of the heart (National Heart Lung and Blood Institute, 2011).

HF is a growing public health concern in Western nations (Chester, 2010). The incidence of HF increases with age, and demographics in the United States reflect an increasing number of persons living with HF. Each year, more than 100,000 people are admitted to a hospital as a result of HF (Nazarko, 2011). HF is the only heart-related diagnosis that is still rising in prevalence. It is the most frequent cause of hospital admission and readmission in the United States (Stuart, 2007). Patients with chronic HF experience a highly morbid and life-limiting illness while suffering from substantial physical and psychosocial burdens (Bekelman et al., 2011). Patients with end-stage HF may have multiple comorbidities including hypertension, type 2 diabetes, renal failure, and hypercholesterolemia (Nazarko, 2011). Although the prognosis for patients with HF has improved over the last decades, the median survival is still about 3 years (Green et al., 2010).

HF remains a chronic condition with permanent ventricular damage and high morbidity and
mortality, especially as the disease progresses (Albert, 2008). The end stage of HF is not a clear-cut or linear process. There is a growing recognition that people who are dying from HF should have access to the same PC as people who have cancer (Nazarko, 2011). The unpredictable trajectory of HF can present barriers to the discussion of end-of-life issues (Green et al., 2010). Patients begin with little to no impact on their functionality and activity tolerance, and progress to severe limits at rest (Heart Failure Society of America, 2012).

**PC Program Components for Patients With HF**

PC focuses on relief of suffering for patients with serious and complex illness to promote quality of life for them and for their family members (Meier et al., 2010) across all care settings such as home care, ambulatory settings, long-term care, acute inpatient care, and rehabilitation centers. It is delivered along with other life-prolonging or curative treatments and is not limited to the care of the terminally ill patient, as hospice care is (Meier et al., 2010).

PC treatment concerns for patients with HF can include medication management, blood pressure monitoring, continuity of care, dealing with emotional and psychosocial needs, supporting quality of life, medical management (Nazarko, 2011), information giving, spiritual support (Flynn et al., 2008), and symptom management, including anxiety, breathlessness, fatigue, cachexia, refractory edema, dyspnea, diminishing renal function and risk of cardiac arrhythmias (Whittingham & Hodgson, 2010). Patient preferences are varied regarding the amount of information they want to receive about their HF prognosis. Variable health beliefs, coping mechanisms, and receptiveness to information all affect the individual needs of each patient in this regard (Green et al., 2010). Although PC is an evidence-based approach for care delivery to patients with HF, less than 10% of persons with HF receive PC services (Hupcey et al., 2009).

**Scientific Evidence: PC and Adult HF**

A review of the evidence about PC and adults with HF provided four themes that are addressed here. First, there is a need to address end-of-life advance care planning. Second, communication between home care professionals and HF patients must be improved about the value of PC. Third, there is a knowledge deficit among HF patients, their caregiving families, and healthcare providers about how PC can be tailored to this population. Finally, symptom management should be a focus along the illness trajectory.

The role of community health providers is important when home care patients are considering end-of-life care planning decisions. Over a 5-year period from 2006 to 2011, research has shown that this area is often overlooked when HF patients’ conditions deteriorate over time. Bekelman et al. (2011) used a descriptive retrospective medical record review to describe a total of 50 adult HF patients’ needs in an outpatient PC program. Over a 3.5-year time period, these patients received 228 outpatient visits (Bekelman et al., 2011). PC program components included advance care planning, hospice/resuscitation status clarification, dealing with fears about the future, care coordination, referrals to other healthcare professionals, and expert symptom management (Bekelman et al., 2011).

Swetz et al. (2011) used a small nonrandomized observational pilot study of 19 patients at a single tertiary care center to assess the benefit of proactive palliative medicine consults and to determine goals of care and quality-of-life preferences for patients with end-stage HF before left ventricular assistive device (LVAD) implantation surgery. The focus of this study was on preparedness planning in this population. Researchers found that this intervention led to improved advance directives completion and availability in the electronic medical records as compared with previous rates.
Kirk (2008) discussed the ethical quandary of deactivation of active automatic implantable cardioverter defibrillators (AICDs) when a patient has reached the end of life to prevent undue suffering during the dying process. The main objectives included the need for recognizing patients have the right to deactivate AICD and the issue that healthcare agencies are obligated to implement policy for identification of patients with AICDs and discussion of deactivation with colleagues, patients, and families.

Whittingham and Hodgson (2010) used a case study design and explored the complexities in implantable cardioverter defibrillator (ICD) deactivation in patients with end-stage HF. The investigator found that complex clinical dilemmas may result when the disease trajectory brings a need to refocus goals of care related to ICDs. Whittingham and Hodgson (2010) addressed the fact that many deactivation discussions take place in the last few days of a patient’s life and may even begin only after a patient with end-stage HF receives shocks. Results highlighted the role of community HF nurse specialists in end-of-life care planning for this population.

Healthcare professionals’ communication with HF patients needs to address the value of PC early in the disease trajectory. Green and colleagues (2010) conducted a narrative systematic review of 18 papers and explored the communication patterns between patients with HF and their healthcare professionals. Specifically, they investigated a potential transition from an active approach to medical care, in which care is focused on cure or chronic disease management, to a palliative approach where the focus is on maximizing quality of life. This systematic review identified that the majority of HF patients wished to have an opportunity to explore both prognostic indicators and their feelings about end-of-life issues. The unpredictable nature of disease progression made it difficult for clinicians to give patients clear prognoses, often in light of multiple comorbidities of older adults with HF. A short case history of a 74-year-old widow was published by Chester (2010) to illustrate how collaboration by cardiologists and PC specialists demonstrated that earlier referral to PC for those with HF ensured optimal care planning and delivery. Indicators for referral to PC in this population included (a) New York Heart Association (NYHA) Classes III–IV, (b) patients thought to be in their last year of life, (c) those with repeated hospital admission for HF, and (d) continuing symptoms despite tolerated treatment. This case study showed that patients do not have to wait until the very end stages of HF to realize a benefit from PC services.

Goodlin’s (2009) review of the literature of adult HF patients indicated the need for PC to be incorporated into the treatment for HF patients at an early stage in the disease process. The discussion regarding medication, diet, exercise, sleep disorders, physical and emotional distress, and information regarding disease trajectory needed to occur early with the patient and family, to allow for understanding and open communication with the healthcare team regarding end-of-life wishes. Goodlin identified three critical questions that clinicians must answer for a HF patient: (a) Does the patient have HF, (b) does the patient have advanced HF, and (c) what therapeutic interventions would improve the patient’s quality of life? PC for HF is a relatively new concept that faces several obstacles to implementation. Clinicians often equated PC with hospice care and cancer patients. In the United States, HF research has often focused on interventions to prolong life so few data guide palliation and support of HF patients.

Evidence points toward a knowledge deficit about what PC is and how it can be provided to this population. As part of two longitudinal studies of a total of 38 spousal caregivers of HF patients, Hupcey et al. (2009) investigated the PC needs of both HF patients and their family caregivers. Spouses expressed a lack of knowledge about what PC is and how it can be provided to HF patients, and discussion of deactivation with colleagues, policy for identification of patients with AICDs when a patient has reached the end of life to prevent undue suffering during the dying process. The main objectives included the need for recognizing patients have the right to deactivate AICD and the issue that healthcare agencies are obligated to implement policy for identification of patients with AICDs and discussion of deactivation with colleagues, patients, and families.

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Millerick (2008) described a model of care in the United Kingdom that encouraged an inclusive approach to identification of chronic HF patients at high risk and provision of integrating PC into clinical practice. There is little robust end-of-life research about HF functional ability, quality of life, symptom prevalence and severity assessment, and decisions about treatment. These authors compiled a Comprehensive Assessment
Checklist (Figure 1) that can be used as a guide to support an HF patient management plan focusing on clarity of treatment, advanced care planning, and priorities of care from the patient’s perspective. They offered this checklist as a practical strategy for integrating a PC model of care into a concurrent healthcare treatment protocol. Similarly, Flynn et al. (2008) offered specific suggestions about the provision of supportive and PC for this population. Using various sources in the National Health System Heart Improvement resource kit, they included dimensions of supportive and PC for a list of common clinical symptoms of end-stage HF, including breathlessness, pain, fatigue, anxiety, limits to physical activity, depression, nocturia, orthopnea, anorexia, cough, and sleeplessness (Box 1). In an article authored by Albert (2008), current issues that limit HF referrals to PC were identified as well as several opportunities to improve patient care through research. There was an increased need for information and training about PC among healthcare professionals, along with improved communication skills. The collaborative care management and focus of PC allowed for referral, treatment, and emphasis on the care of the whole person. This included spiritual, social, financial, goals of care, advocacy, symptom management, and advanced directives.

Because of the variable disease course in HF patients, symptom management needs to be addressed by home care staff at all levels of HF. Zambroski and Bekelman (2008) offered suggestions for effective symptom management for HF patients and their families. Symptoms are burdensome even with patients who are not yet at the end of life, and may be comparable to hospice patients with terminal cancer. Research suggested that HF patients are much less likely to

<table>
<thead>
<tr>
<th>Section I: Clarity of Treatment Status</th>
<th>Yes/No</th>
<th>Date</th>
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</thead>
<tbody>
<tr>
<td>Patient Optimized</td>
<td></td>
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<tr>
<td>NYHA Class III/IV</td>
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<tr>
<td>Unstable for &gt;3 months</td>
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<tr>
<td>ECG: QRS prolongation</td>
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<tr>
<td>Further investigation</td>
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<tr>
<td>If prognosis poor, PC referral</td>
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| Section II: Advanced Planning        |        |      |
| Patient treatment status documented  |        |      |
| DNR status clarified/ documented     |        |      |
| AICD device                          |        |      |
| Device deactivation planned          |        |      |
| Device deactivated                   |        |      |
| Reason for no deactivation            |        |      |

| Section III: Priorities of Care      |        |      |
| Preferred place of care              |        |      |
| Symptom management                   |        |      |
| Medication review                    |        |      |
| Caregiver support                    |        |      |

Figure 1. Glasgow Heart Failure Liaison Nurse Service Comprehensive Assessment Checklist.

Box 1. Dimensions of Supportive and Palliative Care (PC) for Patients With Heart Failure

- Encouraging self-help and support to maximize quality of life
- Involving patients and their carers in treatment and management decisions
- Information giving
- Psychological support
- Symptom control
- Social support
- Rehabilitation
- The use of complementary therapies
- Spiritual support
- PC at the end of life
- Management of dying
- Bereavement care

Notes: AICD = automatic implantable caredefibrillator; DNR = do not resuscitate; ECG = electrocardiogram; NYHA = New York Heart Association; PC = palliative care. Source: Adapted with permission from Millerick (2008).
receive PC treatments than those received by cancer patients. The Symptom Management Model was suggested as an overarching model to identify and address the multiplicity of needs of those with HF living in the community setting. This conceptual approach allowed for comprehensive and ongoing symptom assessment and management and support quality of life for this population. Stuart (2007) presented an evidence-based review of the principles underlying PC for HF patients. Prognosis is strongly predicted by functional status, which declines over the 3 months prior to a patient’s death. Hospitalized patients with reduced renal function (blood urea nitrogen [BUN] ≥ 43 mg/dL and serum creatinine ≥ 2.75 mg/dL) and systolic blood pressure (B/P) less than 115 mm Hg experience 22% in-hospital mortality compared to 2% without those impairments. Several web-based multivariable prognostic models are also available to assist clinicians with prognostic uncertainty. A Web-based prognostic calculator is available at http://www.ccort.ca/CHFriskmodel.asp.

Advanced care planning should be a goal for all patients admitted to inpatient facilities, but should be discussed with this population as much as possible. Four themes were identified in this literature review that included a need to address end-of-life advance care planning, improved communication between home care professionals and HF patients, addressing a knowledge deficit among HF patients, their caregiving families, and improved symptom management along the illness trajectory. These discussions should include their wishes for education and information, decisions about settings of care, assessing quality of life, advance directives, decisions about inactivation of ICDs, and pain and symptom management.

Implications for Home Healthcare Professionals

This evidence suggests there is a large unmet care need for adults with chronic HF and their family caregivers. Home healthcare professionals are in a unique position to develop and maintain relationships with community-dwelling patients with chronic HF over the course of their HF illness trajectory.

Evidence-based strategies to integrate PC into the continuum of care for patients with HF include the following:

- developing and testing educational interventions for home care clinicians, HF patients and their caregiving families about what PC is and how it can be provided in this care setting;
- becoming familiar with the goals and objectives of PC and recognizing opportunities to recommend it for patients with HF;
- developing proficiency in understanding the differences between PC and hospice care and identifying patients who may benefit from either type of care programs in the community;
- using the interdisciplinary nature of PC team to provide care across care settings to meet transitional care needs;
- strengthening case management skill sets to take leadership positions in communicating with healthcare professionals in other settings (inpatient acute hospitals, subacute and acute rehabilitation, nursing homes, or community care/case management) to provide patients with transitional care;
- becoming knowledgeable about HF prognostic indicators in the literature and sharing these with other healthcare providers;
- working with family caregivers to identify community resources to meet all the needs of patients with HF and their family caregivers—physical, psychosocial, emotional, spiritual, and others;
• developing relationships with PC team specialists in your practice area to access services for patients as the needs arise;
• supporting patients with HF and families in planning for what to do in a health crisis;
• providing bereavement support for patients with HF and their families for grief related to loss of functional capacity, roles, and loss of loved ones; and
• encouraging early discussion of advance directives and advanced care planning with patients with HF and their family caregivers so that individualized goals of care may be identified and established across the illness trajectory.

A Call to Action
Home healthcare professionals are in a unique position to identify HF patients who may benefit from PC programs delivered across care settings in the community. By developing ongoing relationships with patients and their family caregivers, we are able to focus on the complete care needs of this patient population and assist them with advanced care planning, psychological and social issues, and symptom management. We can also improve communication among care providers and patients/families to identify goals of care along the trajectory of HF illness.

Returning to the case of Mr. and Mrs. Blake, an individualized PC plan of care will be developed to meet their needs at home. A collaborative interdisciplinary PC team will be developed, consisting of the VN, rehabilitation professionals, social workers, and others who can contribute to Mr. and Mrs. Blake’s care needs. In collaboration with this family, the PC team will identify and develop goals of care. Tailored education will be provided to the home care clinical team about PC in general and more specifically for the HF patient. To implement care across care settings, networking will focus on developing deeper relationships with primary physicians and hospital discharge planners who care for this population in other care settings. Identifying and engaging a HF nurse practitioner to develop prognostic indicators will allow for targeted treatment of the HF patient along the illness trajectory. Finding community resources to meet their needs, which would include resources for managing potential health crises, would provide advance planning for this couple. In addition, timely discussion of advance care directives would promote appropriate care planning in concert with their wishes.

When the focus is comprehensive care of the HF patient and family in the home setting, PC should be incorporated through a multidisciplinary team approach to address concerns to alleviate suffering from chronic conditions such as HF. The HF patient should not have to endure a difficult course over time when early discussions with patients and their families can aid the patient in having a voice on quality of care and end-of-life decisions.

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