This is a revised version of the article published in the June 2014 issue (BCMJ 2014;56:224-229). The authors corrected an error that appeared on page 227, paragraph 1, line 12 in the original article ["(17.2 g twice daily)" corrected to "(17.2 mg twice daily)"].

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Heart failure supportive care

> "What has surprised me is how little palliative care has to do with death. The death part is almost irrelevant. Our focus isn't on dying. Our focus is on quality of life."
>
> —Dr Balfour Mount

ABSTRACT: Heart failure is the only cardiac syndrome still rising in prevalence. Even though heart failure severely affects quality of life and has a high mortality rate, patients with heart failure have less access to palliative care than patients with other life-threatening conditions such as cancer. To address this gap in care, the Heart Failure Supportive Care Clinic was introduced at St. Paul's Hospital in January 2011. The clinic's objective is to improve the quality of life for patients with advanced heart failure who are not candidates for cardiac transplantation or a ventricular assist device. Palliative care specialists can help patients and family members make well-informed and reasonable decisions about preferences for cardiopulmonary resuscitation and when to change to comfort care. Effective communication and a multidisciplinary, team-based approach are needed to ensure a smooth transition to palliative care.

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Dr Balfour Mount is the founding father of palliative care in Canada. He trained in urology at McGill University and in surgical oncology at Memorial Sloan Kettering Cancer Center.

In 1973, Dr Mount organized a seminar based on Elisabeth Kubler-Ross's book *On Death and Dying*. During this seminar, he realized that little was known about the dying process. Patients without disease-modifying options were often left to die in pain and were ignored by the health care team.

Dr Mount knew about St. Christopher's Hospice, located in London, England, and headed by Dame Cicely Saunders. Dame Saunders insisted that if he wanted to study at the hospice he needed to come without his family and immerse himself completely in clinical work. Dr Mount learned the importance of considering the physical, psychological, and spiritual needs of the patient in order to approach the care of the dying holistically.

Dr Mount then decided to conduct a 2-year pilot project to assess palliative care at the Royal Victoria Hospital in Montreal. Initially this effort was met with much resistance; however, the project proceeded and eventually featured an inpatient consultation program, a dedicated palliative care ward, and a bereavement follow-up program. Several years later, after the program proved to optimize patient care, Dr Mount decided to devote his career to clinical palliative care and research, and he published over 130 articles.

His work revolutionized the care of patients with irreversible disease by changing the focus to quality of life. Dr Mount established McGill's biennial International Congress on palliative care. He was awarded McGill's Osler Teaching Award in 1997 and became an Officer of the Order of Canada in 2003. Balfour Mount is currently retired and lives in Montreal with his family.[1,2]

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The recent founding of the Heart Failure Supportive Care Clinic at St. Paul's Hospital was inspired in part by the work of Dr Mount.

Clinical vignette

A 69-year-old man presents to his family doctor with symptoms of severe heart failure (HF). His cardiac function is designated as New York Heart Association (NYHA) class III. Three years before, he had experienced an anterior wall myocardial infarction, was treated with a stent to the left anterior descending artery, and was prescribed metoprolol, ramipril, simvastatin, and acetaminophen. Echocardiography demonstrated a left ventricular ejection fraction (LVEF) of 20% and an implantable cardioverter defibrillator (ICD) was placed. Subsequently he was admitted to hospital six times with decompensated HF. During the last two admissions he received intravenous furosemide and dobutamine, which improved his dyspnea. During treatment he has not consistently complied with medication, diet, fluid restriction, and exercise recommendations. Three months ago he received two appropriate ICD shocks for unstable ventricular tachycardia. His family doctor discussed the home "do not attempt to resuscitate" (DNAR) order, but the documentation was not completed. The patient has now been readmitted to hospital with decompensated HF and severe dyspnea. What is the best way to assess and treat this patient?

Heart failure

Many patients with NYHA class III or IV heart failure have reported such poor quality of life that they would be willing to "trade in" half of their remaining life to feel better.[3]

HF is the only cardiac syndrome still rising in prevalence. In British Columbia, 1% of the population has HF.[4-6] The mortality rate in patients with HF is high and the overall approximate survival rates are 66% for 1 year, 50% for 2 years, and 35% for 5 years, similar to cancer.[7,8] In patients with NYHA class IV heart failure, hypotension, LVEF less than 25%, and no prospect of becoming candidates for advanced therapies, life expectancy is less than 9 months. Despite these facts, only about 10% to 20% of HF patients receive palliative treatment.[9]

Patients with HF usually have symptoms long before they present for evaluation. Even with the initiation of appropriate medications, diet, and fluid restriction, symptoms almost always persist at some level. These symptoms affect daily activities, work, interpersonal relationships, and overall quality of life.[10]

The ACC/AHA 2005 Guideline Update for the Diagnosis and Management of Chronic Heart Failure in the Adult provided class I recommendations for the inclusion of palliative care for patients with advanced HF. Despite this, palliative care for HF remains grossly underused, especially compared with palliative care for cancer.[9] Many authors have proposed that the reason for this is that prognostication is much less reliable for HF than for other life-limiting illnesses. Patients with advanced HF usually follow a slow clinical decline characterized by multiple, unpredictable exacerbations. In contrast, patients with advanced cancer often maintain a satisfactory level of functioning until they have a clinically significant downturn in their disease process.[5]

Although prognostication in HF is difficult, we recommend focusing early on symptom management. Most patients can be managed in the community by their family physicians. However, patients who have complex multisystem disease, a high symptom burden, poor quality of life, or psychosocial distress should be referred to a palliative medicine specialist.

Palliative care for heart failure

Palliative care has historically been associated with cancer care. However, the provision of palliative care to patients with advanced HF to prevent patient suffering is just as important.[11]

Palliative care includes multiple disciplines, including geriatrics, respiratory therapy, psychiatry, psychology, dietetics, occupational and physical therapy, and social work, and requires a team-based approach. The team addresses symptoms and distress in both the patient and family, who should be treated as a single unit since the well-being of one affects the other.

Patient classification can help guide treatment. For instance, in a patient with NYHA class IIIB heart failure (moderately symptomatic with recent rest dyspnea), early and clear communication regarding the appropriateness of advanced therapies, such as heart transplantation or implantation of a left ventricular assist device (LVAD) while awaiting transplantation, is very important. The communication component is essential as it can affect patient expectations about future treatment.

Patients with complex multisystem disease, advanced HF, and moderate to severe symptoms should be followed by a cardiologist and palliative care physician concurrently. Palliative treatment should integrate appropriate evidence-based medical and surgical treatments to address cardiac pathology. For instance, an ACE inhibitor can reduce symptoms of HF and should be continued, if tolerated, even if the patient has advanced disease.[10]

Evolution of advanced HF treatment

Some consider HF palliative care as adjunctive treatment that should be initiated only when standard HF treatment fails. This model is outmoded as many patients with advanced HF experience severe symptoms and would benefit from symptom management. Unlike cancer patients who can be asymptomatic for long periods of time, patients with advanced HF always have symptoms and rarely ever feel entirely well.

Patients with advanced HF who experience a severe exacerbation are often treated by their cardiologist with aggressive diuresis and other treatment as opposed to supportive care alone. Patients dying from HF receive much more life-prolonging treatment than those dying from cancer, as oncologists tend to discontinue chemotherapy before the patient enters end-stage disease.

Although many prognostic features, including biochemical, hemodynamic, electrophysiological, and demographic ones, have been studied, none are better than clinical judgment. For ambulatory patients the Seattle Heart Failure Model (www.seattleheartfailuremodel.org) has been validated as a prognosis tool for HF patients and provides 1-, 2-, and 3-year survival rates. This model, however, is not applicable to admitted patients. For admitted patients, the Enhanced Feedback for Effective Cardiac Treatment (EFFECT) prediction score is used to predict risk of death at 30 days and 1 year. Since the data required for this score do not include LVEF, the EFFECT model (www.ccort.ca/Research/CHFRiskModel.aspx) applies to both systolic and diastolic HF.

Cardiac cachexia, central sleep apnea, and depression all increase HF mortality.[5] Serum b-type natriuretic peptide (BNP) may be helpful for prognostication as well, since BNP levels correlate with HF symptoms and, in one study, even to risk of death at 31 days (if the pre-discharge BNP level was greater than 700 pg/mL).[12]

Palliative treatment of advanced heart failure

Treatment for advanced HF patients should include standard medications such as ACE inhibitors, ARBs, and beta-blockers as these can improve symptoms and quality of life. In the Carvedilol Prospective Randomized Cumulative Survival (COPERNICUS) trial, the use of carvedilol appeared to improve quality of life after only about 10 months.[13] Thus, in most patients, standard HF treatment should continue with the aim of improving quality of life.[5] Patients with HF develop a multitude of symptoms, including fatigue, dyspnea, cognitive impairment, and depression. Although dyspnea in HF is related to volume overload and pulmonary edema, it is also related to generalized myopathy. Even in patients with diastolic dysfunction who have preserved systolic function, similar pathologic inflammatory and neuroendocrine maladaptive processes occur that lead to dyspnea and pain.[5]

The Edmonton Symptom Assessment Scale (ESAS) is a nine-symptom questionnaire that uses a visual analog scale from 0 (no pain) to 10 (worst possible pain) to rate the severity of symptoms. When assessing patients it is important to capture the frequency and severity of symptoms and the degree of limitation in specific activities that symptoms cause.

Dyspnea

Dyspnea is the most common distressing symptom in advanced HF and needs to be treated even if the clinical, radiographic, or biochemical features of the case do not suggest it.[14] Treatment needs to be escalated until the patient reports subjective improvement. For volume overload, intravenous administration of high-dose loop diuretics is required. The addition of metolazone may be required if resistance to loop diuretics develops. Dyspnea in HF may also be due to fatigue, deconditioning, and anemia caused by chronic disease.

It is important to remember that standard measures of dyspnea rely on the patient's self-report, and patients nearing the end of life with declining consciousness and cognitive ability may be unable to report, even by yes or no answers, distressing dyspnea. This makes the patient vulnerable to undertreatment or overtreatment. Diagnostic options such as asking family members to participate in the patient's evaluation may help to estimate dyspnea.[15]

Opioids are the mainstay of treatment for symptomatic dyspnea. The safest and most reliable way to dose opioids in naive patients is to use a dose-finding regimen. This method begins with the administration of opioids on an as-needed basis. Once an estimate of the total daily dose is achieved, then the opioid can be administered regularly (usually every 4 hours). The oral route is preferred to the subcutaneous route, and there is rarely a role for intravenously administered opioids. Depending on the severity of the shortness of breath, we would start an opioid-naive patient with immediate-release oral hydromorphone at 0.5 mg every hour until the dyspnea improves. If the total 24-hour dose of PRN opioids is 3 mg, then we would transition the patient to 0.5 mg of oral hydromorphone every 4 hours regularly. The hourly PRN dose must remain for breakthrough dyspnea. In this example, the oral hydromorphone should still be dosed at 0.25 to 0.5 mg PRN hourly. After 2 days, if minimal breakthrough doses (i.e., fewer than three doses) are required, then the patient can be transitioned to long-acting hydromorphone (every 12 hours). The minimum dose of the long-acting formulation of hydromorphone is 3 mg twice a day. This transition decreases pill burden and can thus improve quality of life. Constipation should be anticipated and sennosides (17.2 mg twice daily) and prune juice (30 mL daily) should be commenced concurrently with opioids. Other side effects, including nausea, pruritis, and dizziness need to be discussed with the patient and treated.[16] In patients with renal impairment, opioids other than hydromorphone are preferred.

Benzodiazepines may be helpful in the treatment of dyspnea associated with anxiety.[17] The use of supplemental oxygen does not improve symptoms in patients with mild hypoxemia, but directing fast-flowing air at the face (i.e., using a fan) can help. Advice on posture and relaxation techniques may also be helpful. Sleep-disordered breathing, such as central sleep apnea, should also be considered. In the appropriate patient, the use of continuous positive airway pressure devices can improve symptoms.

Pain

About 40% of patients with advanced HF have pain and most are dissatisfied with the degree of pain control achieved.[18] The cause of pain is likely multifactorial and includes angina, diabetic neuropathy, musculoskeletal pain, and pain from intestinal edema.[19] The use of beta-blockers, calcium channel blockers, and nitrates may reduce ischemia and pain.

Surgical or percutaneous revascularization should be considered for symptom relief in patients with intractable angina. Opioids, as prescribed for dyspnea, are often necessary to achieve pain control. Opioids can be administered orally, subcutaneously, by transdermal patch, or by intravenous infusion. Nebulized opioids can also prove useful. Implantable spinal cord stimulators are used for palliation of refractory ischemic pain. These devices, controlled by the patient, function by taking advantage of the gate theory of pain. The stimulator is implanted directly in the epidermal space where anginal symptoms occur (T2 to T5 dermatomes).[19]

Palliative care has historically been associated with cancer care. However, the provision of palliative care to patients with advanced HF to prevent patient suffering is just as important.

Cognitive impairment and depression

Patients with advanced HF have decreased cerebral perfusion and can have memory, attention, and cognitive impairment.[19] Given the negative effect of advanced HF on quality of life it is not surprising to find increased incidence of depression and anxiety. Treating physicians should ask questions to determine the presence and extent of cognitive symptoms. Depressed patients have higher mortality when compared with nondepressed patients.[20] Pharmacological and nonpharmacological treatments should be considered, including selective serotonin inhibitors (SSRIs) and psychological counseling.

Thromboprophylaxis

Advanced HF patients have a higher risk of severe left ventricular (LV) or systolic dysfunction and thus cardiac thromboembolism. Anticoagulation is ordinarily required in patients with LV dysfunction in combination with LV thrombus or atrial fibrillation. However, in advanced HF patients, the decision to anticoagulate must be considered very carefully as such therapy has its own risk and requires careful monitoring. Each case should be reviewed within the team and the benefits and risks of anticoagulation should be discussed with the patient and family.[21]

Communication

Although the goal of therapy for most patients with advanced HF is to extend life, an acknowledgment of the life-limiting nature of the disease is required. Most patients appreciate an honest and early discussion about these issues and the goals of care to help them express their wishes and prepare for end of life. Poor doctor-patient communication has been found to result in advanced HF management plans that do not take the wishes of patients into account in about one-third of cases.[22]

Destination therapy for advanced heart failure

Fewer than 1% of patients with HF will receive a heart transplant. The LVAD was initially designed to temporarily support patients awaiting heart transplant (known as "bridge therapy"). In 2002, the US Food and Drug Administration also approved the device as an alternative to transplantation, referred to informally as "destination therapy." In the US, patients with NYHA class IV heart failure, systolic dysfunction (ejection fraction less than 25%), inotrope dependency, or low peak oxygen consumption (less than 12 mL/kg/min) are required to qualify for destination therapy. In the REMATCH study, LVAD therapy compared with medical therapy alone prolonged life. Depression and health-related quality of life were also improved in LVAD patients. However, the complication rates for LVADs are significant and include stroke, bleeding, multiorgan failure, and thromboembolic disease. Health Canada has not yet approved LVADs for destination therapy.

Heart Failure Supportive Care Clinic

The Heart Failure Supportive Care Clinic was introduced at St. Paul's Hospital in January 2011, and later at Vancouver General Hospital. The objective of this clinic is to improve the quality of life for patients with advanced HF who are not candidates for transplantation or an LVAD. All our patients have advanced HF (NYHA III or IV) with complex medical conditions. Despite appropriate medical management, they still have moderate to severe symptoms as measured by ESAS or similar tests. Patients can be referred to the clinic if they are not improving symptomatically with standard treatment or palliative care is prescribed by their family practitioner, general internist, or cardiologist.

Patients are reviewed by the clinic's palliative care physician, cardiologist, and nurse, and a detailed assessment and management plan is developed and transmitted to the patient's doctors and home care team. Multiple visits are often required to control the patient's symptoms and to have the opportunity to discuss issues such as ICD deactivation, DNAR status, and other patient preferences.

Our approach prioritizes patient preferences, especially with respect to where they would like to live as they approach end of life. For instance, many patients prefer to be at home; however, they often end up in hospital because of limited home support. In our view, this indicates that further resources and effort need to be applied to community palliative care programs so that these patients can remain comfortable at home.

We are currently reviewing data on the first 100 patients served at the Heart Failure Supportive Care Clinic, and we hope to analyze and publish our findings shortly. Our hypothesis is that patients assessed and managed in the clinic will have improved quality of life and fewer admissions to hospital for decompensated HF. We are also working to develop guidelines and tools to help health care providers in British Columbia care for patients.

Back to the clinical vignette

So what is the best way to manage our 69-year-old male who presents with NYHA class III heart failure, is not a candidate for advanced therapies, does not have a clear care plan, and has not complied with treatment recommendations?

The care for this patient should focus on symptom management and quality of life. Given the severity of the patient's dyspnea, our recommendation would be to admit him to a palliative care unit. Clinical history taking that identifies symptoms and a physical examination that assesses volume status, cardiac function, and respiratory function should follow. A trial of intravenous furosemide and oral metolazone would then be reasonable; we would not recommend inotropes as they are unlikely to improve symptoms or quality of life at this stage.

A subcutaneous fentanyl infusion may be used to rapidly improve his dyspnea. Fentanyl, in this case, could be dosed in a broad range. For example, in the opioid-naive patient, the dose could be fentanyl 25 to 100 μg/h infusion, titrated up by 25 μg/h to patient comfort. Breakthrough doses of subcutaneously delivered fentanyl should be available for dyspnea or pain. Fentanyl is a good choice of opioid in this case as it can be readily titrated, may have fewer side effects, and is less likely to cause symptoms in renal failure. It is also less deliriogenic than other opioids.[23]

As part of transitioning to a comfort care pathway, only limited investigations, such as a chest X-ray, should be performed to assess severity of volume overload. Measurement of vital signs may be helpful in cases if clinical status worsens and an objective measure is needed for comparison purposes. Otherwise, it is important to discuss the patient's clinical status with family and to identify a temporary substitute decision maker. Once the patient is stabilized, a family meeting should occur to discuss and clarify goals of care and outline the discharge plan.

Conclusions

Heart failure is a major health care problem that can severely affect quality of life. Patients with heart failure have less access to palliative care than patients with other life-threatening conditions such as cancer. Research has shown that heart failure supportive care should be introduced when advanced heart failure (NYHA class III or IV) is identified, and as soon as the patient experiences increased severity of symptoms.

Preferences for cardiopulmonary resuscitation and when to change to a comfort care pathway should be discussed with patients well in advance. Palliative care specialists can help patients and family members make well-informed and reasonable decisions. Effective communication and a multidisciplinary, team-based approach are needed to ensure a smooth transition to palliative care. The cardiologist, family physician, and palliative care specialist are responsible for educating the patient on disease prognosis and treatment options.

We need to pay close attention to Dr Mount's important work showing that palliative care is required and essential when treating symptomatic patients with advanced disease such as heart failure.

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Competing interests

No competing interests.

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