

Integrated End-of-life Care in Advanced Congestive Heart Failure: Where Are We Now?

Helen Senderovich^{2,3,4} (MD MCFP (COE) (PC)), Justin Chow¹ (MD), Shaira Wignarajah³

¹Department of Medicine, University of Calgary, Canada; ²Faculty of Medicine, University of Toronto, Canada; ³Baycrest Health Sciences System, Toronto, Canada; ⁴Department of Family and Community Medicine, Division of Palliative Care.

Introduction

Congestive Heart Failure (CHF) is a terminal diagnosis that affects 5.7 million Americans \geq 20 years old, and this number is increasing.¹

Mortality = **50%** at five years after diagnosis.^{2,3}
 Median survival after first CHF-related hospitalization = **2.4 years**.⁴
 CHF symptoms: dyspnea, pain, peripheral edema, fatigue, depression

Health care providers, allied care workers and the general public need heightened awareness of the morbidity and mortality associated with CHF.

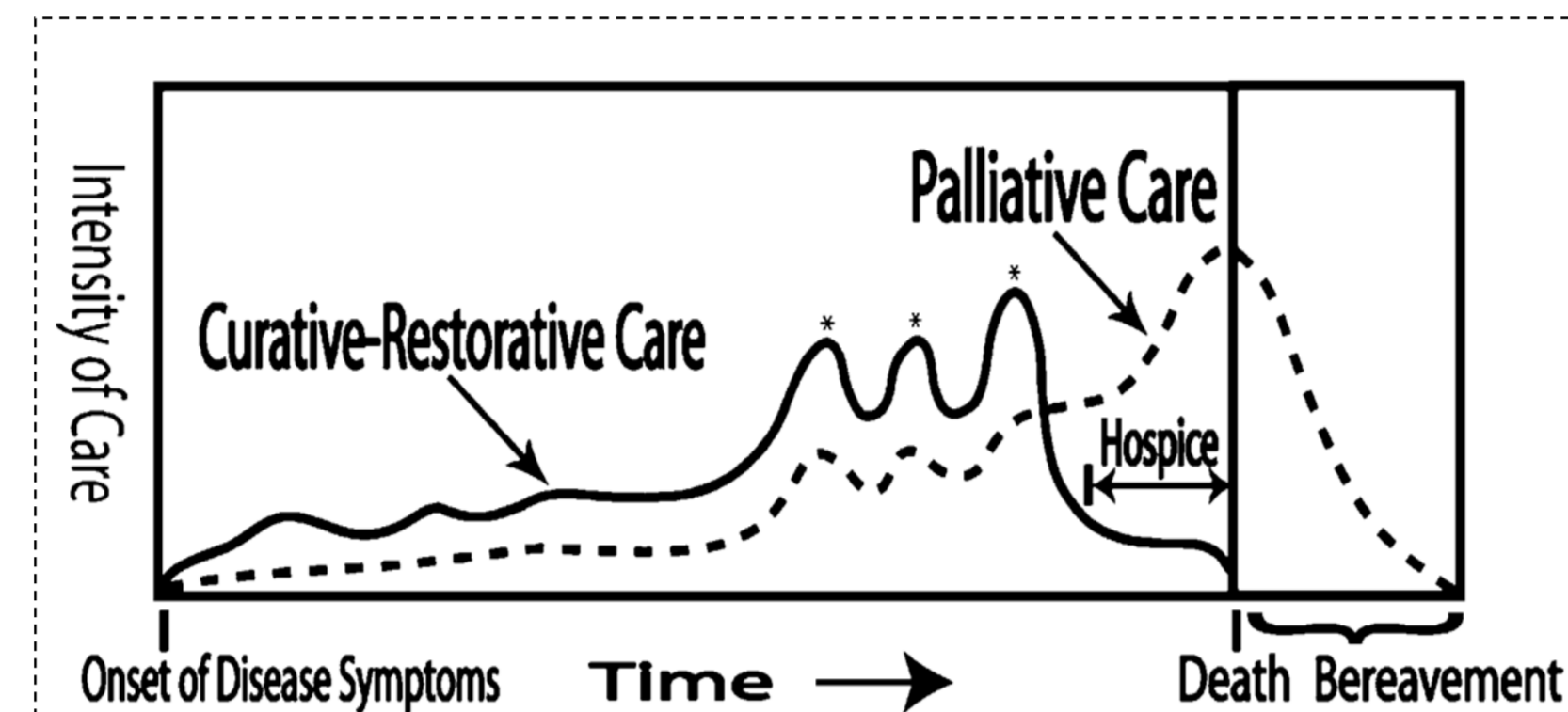


Figure 1. Individualized integrated model of palliative care in which a patient receives palliative care (dashed line) at the onset of symptoms concurrently with curative/restorative care (solid line) in an individualized manner. Like curative/restorative care, the intensity of palliative care increases and decreases to reflect the needs and preferences of the patient and the patient's family. The asterisks indicate periods of high intensity of curative/restorative care (e.g., hospitalization or CHF exacerbation). Reprinted with permission from Lanken et al., Am J Respir Crit Care Med 2008.

Key Challenges in Delivering Palliative Care in CHF

1 Prognostication: There are **no good models** to predict mortality in CHF due to its complex and unpredictable disease course.⁷ In the heart failure literature, NYHA class²⁰, number of hospitalizations⁴ and functional capacity (as determined by VO₂ max testing)²¹ have been used as clinical indicators to evaluate prognosis. Biochemical markers such as N-Terminal prohormone of brain natriuretic peptide (NT-BNP) have also been shown to correlate with disease severity.²² However, the use of the above methods to prognosticate heart failure has been met with limited success. The most promising are the Seattle Heart Failure and HFSS scores.¹² The Gold Standards Framework is used to provide patients with advanced disease the 'best' care that is possible. It involves three steps¹⁹:

- Identify the people who are in need of special care
- Assess and record their needs
- Plan and provide their care

Recommendation: Exposure, education and recognition

2 Systematic barriers to accessing PC: **Limitations in knowledge** about PC in patients, families and providers foster the stigma of "treatment failure"^{8,9} and "giving up"¹⁰, thereby preventing PC referral. As such, palliative care is misinterpreted as being a service that is only used for those who are nearing death¹⁷ It has been found that many primary care and cardiology providers in particular, were not aware that palliative care is not prognosis dependent, and can be provided alongside life-prolonging therapy.¹⁷ Literature shows that the underuse of palliative care is due to poor implementation of palliative care and inadequate referral to palliative care.¹⁶ In fact only 20-30% of the 250,000 patients in need of PC, are referred.¹³ Moreover, it has been found that many patients wish to speak about end of life care with physicians, but no one had initiated the topic.¹⁸

Recommendation: Provide education to address misconceptions and stigma, but treat supportively and guide patiently.

3 When is it time (to refer)? PC is inappropriately associated almost exclusively with pre-death care with no clear direction as to when it is best to refer patients.¹¹ Literature shows that most providers decide to implement PC based on certain 'triggers' such as presence of certain physiological symptoms, a functional decline in disease status, events such as a device implantation, and repeated hospitalizations over a short period of time (e.g. 3-6 months).¹⁷ But, based on AHA/ACCF, and CCS guidelines, it is **best to integrate PC at the time of the diagnosis**.⁵

Recommendation: Focus on early advance care planning within an individualized integrated model (Figure 1).

4 Who co-ordinates care? A CHF nurse may be the best person to co-ordinate the provision of services, but general practitioners feel it is their responsibility.⁹ **Whether it is the CHF team nurse, cardiologist, or family physician, is not clear**. The literature search showed one previous collaborative team-based model for palliative care in heart failure patients, which enabled 50% of patients to be able to die at home, with only 8.3% of all patients requiring a formal consultation by a palliative physician.²³

Recommendation: Develop a seamless multidisciplinary, team-based approach

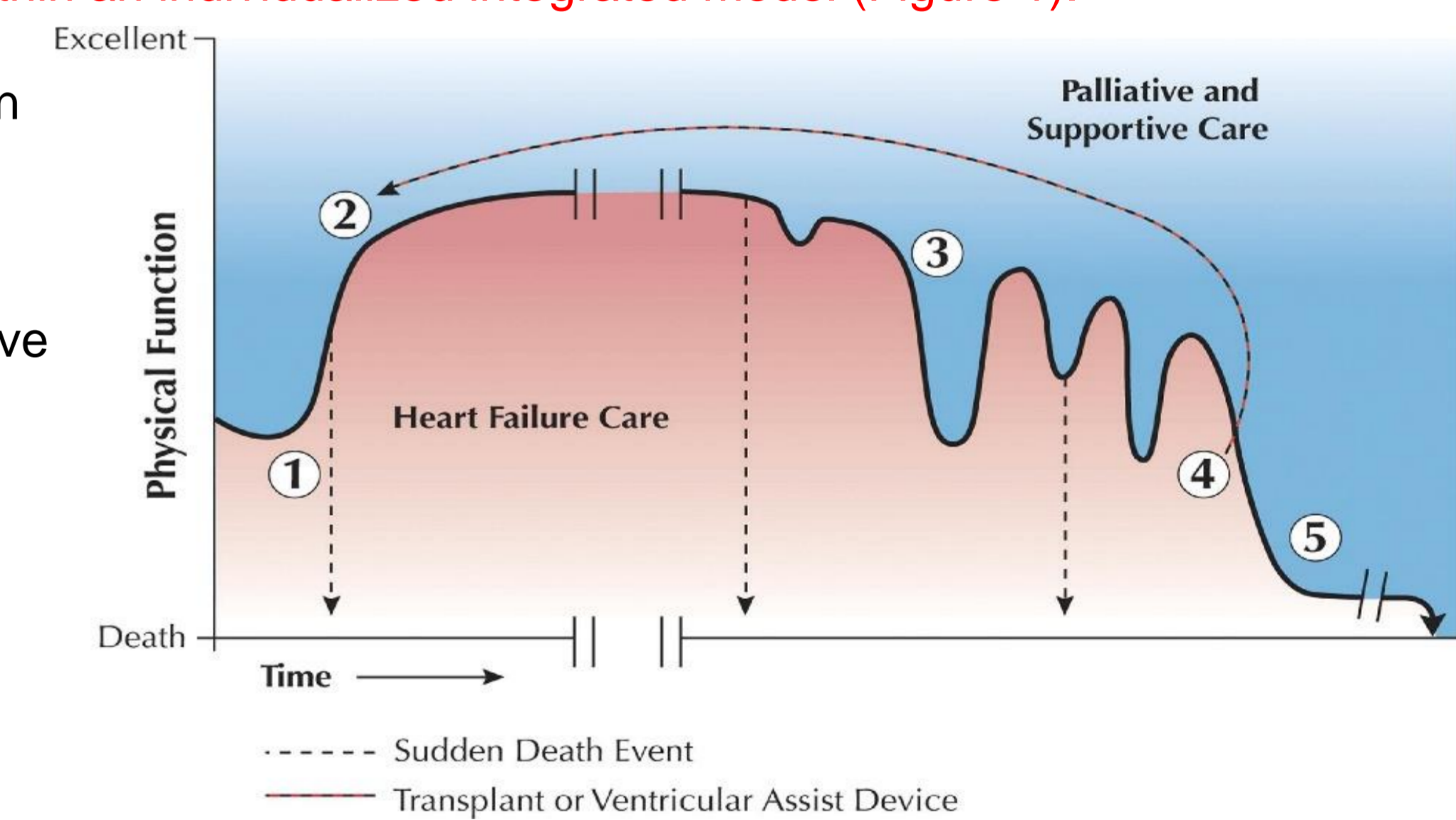


Figure 3. Schematic depiction of comprehensive heart failure care. In phase 1, the initial symptoms of CHF develop and medical treatment is initiated. In phase 2, a plateau of variable length is reached with medical management. In phase 3, functional status declines with intermittent CHF exacerbations that respond to rescue efforts. Phase 4 and 5 represent refractory end-stage CHF and subsequent end-of-life function. Reprinted with permission from Goodlin, JACC 2009.

Objectives and Methods

1. To review the literature under "palliative care", "palliative medicine", and "heart failure" from 1995 onwards. Only two RCTs are available:

A) Brännström & Boman (study period: Jan 2011 – Oct 2012) compared **usual care to palliative home care** using a protocol they referred to as the "PREFER" model. Their sample consisted of 62 patients with New York Heart Association (NYHA) class III/IV symptoms. Prospective assessments were made at 1, 3, and 6 months. Patients randomized to the PREFER model experienced:

- Improved health-related quality of life
- Improved self efficacy
- Decreased nausea
- Decreased total symptom burden
- Fewer re-hospitalizations
- Improved NYHA symptoms.¹⁴

B) Sidebottom et al compared **palliative care referral patients to patients in usual inpatient care**. Their sample consisted of 232 patients who were hospitalized with decompensated CHF. They were from a large tertiary-care urban hospital and were recruited over a 10-month period. Primary outcomes were measured at baseline, 1, and 3 months. Secondary outcomes included advance care planning (ACP), inpatient 30-day readmission, hospice use, and death.

- Patients referred to palliative care experienced:
- Decreased total symptom burden
 - Improved health-related quality of life
 - Decrease in depressive symptoms.¹⁵

2. To formulate recommendations for end-of-life care in patients suffering from CHF and to describe the challenges in integrating palliative care.

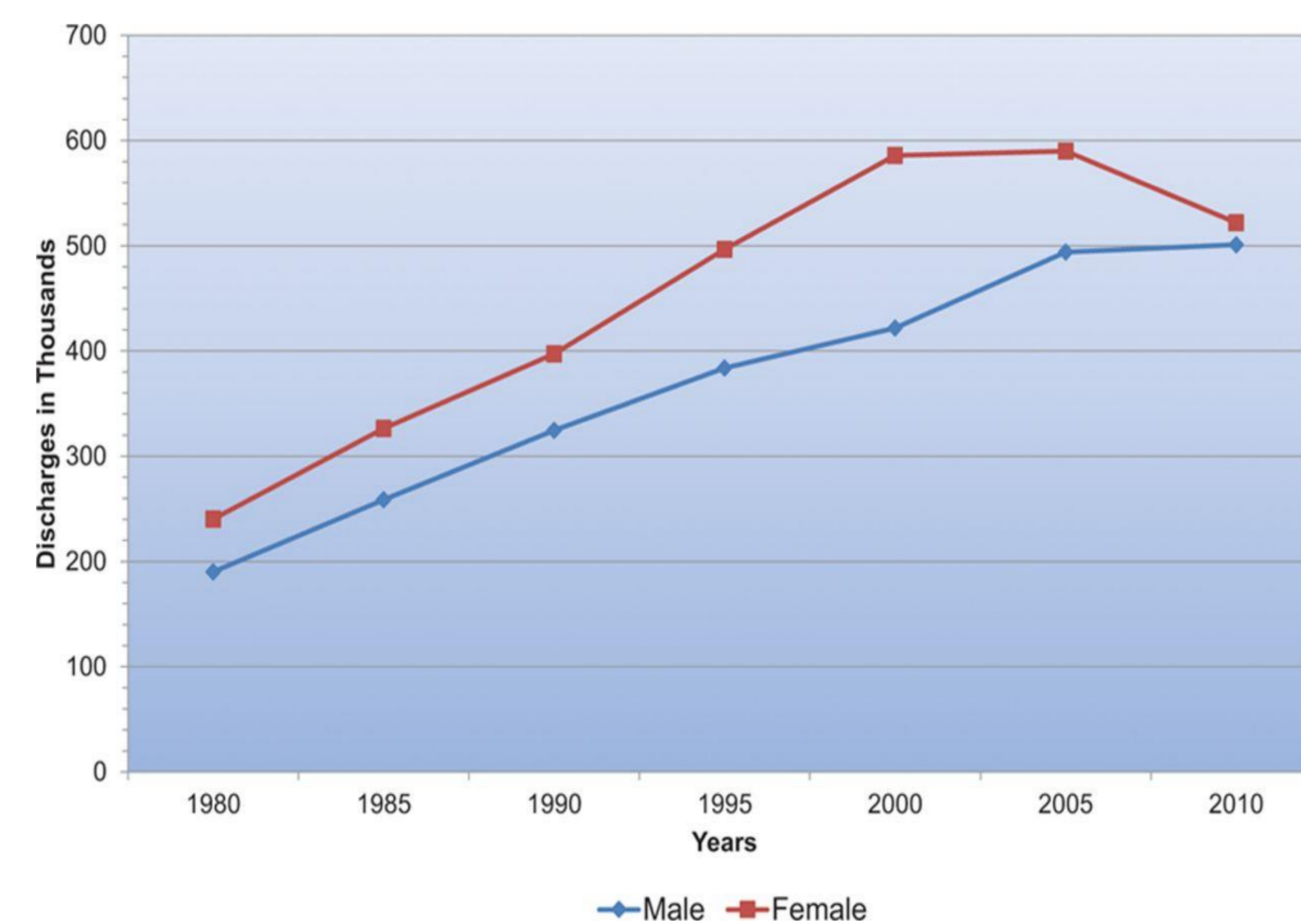


Figure 2. Hospital discharges for heart failure by sex (United States: 1980-2010). Reprinted with permission from Mozaffarian et al., Circulation 2014. This figure uses data from the United States to illustrate the point that prevalence is increasing for individuals with CHF. There is no easily accessible Canadian data.

Conclusions and Next Steps

- PC has a role in managing CHF symptoms (dyspnea, fatigue, peripheral edema, pain) simultaneously alongside curative modalities (ACE-inhibitors, beta blockers, aldosterone antagonists) (Figure 1). Antidepressants, opioids, and digoxin can provide symptomatic relief.
- Barriers to accessing PC services include pre-existing misconceptions, difficulty prognosticating, and uncertainty about co-ordinating care and timing referral.
- A multidisciplinary team-based approach is essential for delivering effective integrated PC to patients suffering from CHF.
- **Next steps:** Further study into co-ordination of multidisciplinary care teams and multi-center trials with longer follow-up in both inpatient and outpatient settings.
- **For further inquiry:** Please contact Dr. Helen Senderovich at hsenderovich@baycrest.org

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