COLLABORATING WITH PALLIATIVE CARE TEAMS TO PROVIDE END OF LIFE CARE FOR PATIENTS WITH HEART FAILURE: AN INTEGRATIVE REVIEW

by

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Abstract

Advanced heart failure (HF) can be difficult for nurse practitioners (NPs) to manage in primary care due to the unpredictable nature of the condition. Further, barriers that patients with HF experience in regards to receiving end of life (EOL) care hinder NP collaboration with palliative care teams. The goal of the project is to answer: How can NPs working in a primary care setting collaborate with palliative care teams to provide patients who have HF with EOL care? A literature search was conducted using the Cumulative Index of Nursing and Allied Health, PubMed Medline, PsychInfo, Social Work Abstracts and the National Guideline Clearinghouse electronic databases. Evidence was also gathered using backward and forward reference searching, and highly relevant grey literature from the BC Heart Failure Network. The Canadian Interprofessional Health Collaborative (CIHC) framework was used to describe the theoretical underpinnings of this paper by outlining the factors involved to achieve interprofessional collaboration. There were 33 articles retrieved during the literature search to inform how NPs can collaborate with palliative care teams for patients with HF at EOL. There were no articles that answered the research question directly. Instead, barriers and issues for patients with HF receiving EOL care were identified in the findings. Nurse practitioners can collaborate with palliative care teams by addressing the barriers to EOL care for patients with HF that relates to communication, leadership, role clarification, team functioning, and conflict resolution. Nurse practitioners should be encouraged to collaborate with palliative care teams to improve accessibility to palliative care for patients with HF at EOL. Future research is needed to directly inform how collaboration can occur with palliative teams to provide patients who have HF with EOL care.

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I have been fortunate to care for patients with heart failure in a community heart function clinic setting. This experience has allowed me to play a role in the care that patients with heart failure experience at end of life and as such, I have found that often their end of life needs go unmet. In my experience, palliative care is not particularly implemented well despite the emergence of this topic amongst the heart failure community and subsequent resource development. One of the main issues is that palliative and end of life care can be difficult to identify in heart failure due to the unpredictability of the condition. Second is that in my experience, palliative care and end of life are not often discussed in practice with busy clinic visits. If discussions do take place, they are often limited to code status and medication withdrawal. Talks that do occur with patients are often limited to “you should get your affairs in order” or “there’s not much else we can do”. Without comprehensive care discussions, the needs, wishes, values, and preferences of patents with heart failure are not brought to the forefront and implemented during end of life. Third, care providers frequently draw upon guidelines to direct practice and in the case of heart failure care during end of life the available resources to guide this care are often not utilized. As a result of these issues, patients approach end of life feeling frightened and alone. As a practitioner, I have seen the emotional turmoil this has placed on our patients with heart failure and have myself experienced a sense of helplessness in regards to how to resolve this gap in care.

Dedication

I dedicate this project to:

- My children, Oliver and Isabel, whose unconditional love continually inspire my drive to achieve;
- My husband, Chris, whose support allowed me to persevere in the program;
- My parents, Emily and Ben, whose love and commitment to helping with Oliver and Isabel allowed me to focus on my studies;
- My in-laws, Stephanie and Dziadek, who were also consistently open to helping with Oliver and Isabel; and finally,
- My two sisters-in-law, Arleta and Kathy, who would always be available at the last minute to help with Oliver and Isabel.

CHAPTER 1

Introduction

The unpredictable nature of advanced heart failure (HF) can make this condition difficult to manage in primary care. Even though guidelines exist that provide direction for managing HF in the advanced stages, not all patients receive care that completely reflects these recommendations (Wordingham, McIlvennan, & Dionne-Odom, 2016). Guideline recommendations indicate that palliative care teams should be coordinating care for patients with HF at end of life (EOL) (Yancy et al., 2013) yet there is a limited amount of evidence to support this in practice (Wordingham et al., 2016). Providing care for patients with HF at EOL can be challenging for primary care providers as palliative care service tends to be limited in primary care settings (Yancy et al., 2013). Despite the availability of resources to guide care for patients with HF at EOL, the current use of these resources in primary care practice often go underutilized (Kimel, Simpson, & Ignaszewski, 2014). As primary care providers, nurse practitioners (NPs) play a key role in managing the care for patients with HF at EOL. To optimize and improve EOL care for patients with HF, collaboration is needed amongst care teams given the lack of uptake of available resources to guide EOL care.

The project seeks to answer the question: How can NPs working in a primary care setting collaborate with palliative care teams to provide patients who have HF with EOL care? It is imperative to note that answering *how* NPs can collaborate is a rather complex topic. The methodology of the project is in the form of an integrative review. Review of the findings provides practice recommendations for NPs including clinical implications and areas needed for future research.

CHAPTER 2

Background and Context

The rate and prevalence of HF in adults, those over 18 years of age, is increasing (Jaarsma, 2005). Compared with all other health conditions for older adults aged 65 years and greater, HF is responsible for most admissions to hospital (Howlett, 2009). According to the Canadian *Chronic Disease and Injury Indicator Framework* (2016), HF prevalence among those greater than 40 years of age is 3.6% with an incidence rate of 522.6 per 100,000 persons (Public Health Agency of Canada, 2009). The prevalence of HF is particularly noteworthy because the majority of patients are older adults (Ahmed, 2003). Heart failure is a common diagnosis upon discharge from hospital, also amongst older adult populations (McAlister, Stewart, Ferrua, & McMurray, 2004) with an average one year mortality rate of 33% (Lee et al., 2004). In light of the high mortality rate, not all patients with HF receive the palliative EOL care that they should.

End of life care, a component of palliative care, is considered to be care that is offered once a patient approaches death. Estimates show that only 15% of Canadians have access to EOL care when they need it (Quality End of Life Care Coalition of Canada [QELCCC], 2017), a concerning reality that heavily impacts patient quality of life (QoL). As a result, many Canadians die without adequate pain relief, feel isolated with a loss of dignity, and experience fear as they approach death (QELCCC, 2017). As HF is a progressive and life-limiting condition, it is essential that primary care providers identify when a patient is nearing or at EOL. Due to the unpredictable nature of the HF disease process, identification of EOL is often difficult. To provide patients who have HF with EOL care and to better support the patient's QoL vision, NPs should collaborate with palliative care teams. This chapter will identify and define the main concepts including HF, EOL, palliative care, NPs, primary care, the palliative care team, and collaboration. Additionally, this chapter will explore the barriers to patients receiving palliative care in the setting of HF as these barriers considerably hinder NP collaboration with palliative care teams. Barriers that impact multidisciplinary care for patients with HF at EOL include the unpredictable disease trajectory of HF, a lack of consensus regarding a standard definition of palliative care in HF, and a lack of communication.

Concepts

Heart failure. There are several classifications and stages of HF that NPs should consider while collaborating with palliative care teams for patients at EOL. For the purposes of this paper, HF will be defined as "a clinical syndrome defined by symptoms suggestive of impaired cardiac output and/or volume overload with concurrent cardiac dysfunction" (British Columbia [BC] Government, 2015, para 8). According to the Canadian Cardiovascular Society consensus conference recommendation (2006), HF classification is according to symptom severity with functional capacity categorized by the New York Heart Association (NYHA) system I-IV; Class I (no limiting symptoms), Class II (symptoms with less than ordinary activity), Class III (symptoms with regular activity), and Class IV (symptoms with no exertion) (Arnold et al., 2006). Further, the American College of Cardiology and the American Heart Association (ACC/AHA) Task Force (2005) classifies HF into stages A though D; Stage A (asymptomatic, no structural heart disorder), Stage B (asymptomatic, structural heart disorder present), Stage C (symptomatic; current or past structural heart disorder), and Stage D (patients with HF at end-stage) (Hunt et al., 2005).

The signs and symptoms of HF commonly include: dyspnea, orthopnea, paroxysmal nocturnal dyspnea, fatigue, weakness, exercise intolerance, dependent edema, cough, weight gain, abdominal distention, nocturia, and cool extremities (Arnold et al., 2006). Other signs and symptoms less commonly associated with HF include: cognitive impairment, altered mentation or delirium more common in the elderly, nausea, abdominal discomfort, oliguria, anorexia, and cyanosis (Arnold et al., 2006). Symptoms of *advanced* HF may include recurrent exacerbations, functional limitations, resistance to pharmacotherapeutic therapy, increased diuretic dosing, worsening renal dysfunction, hypotension, weight loss, and recurrent implantable cardioverter defibrillator (ICD) shocks (Hauptman & Havranek, 2005). A unique feature of HF is that there can be movement between NYHA class and stage. The HF disease process does not always follow a progressive predictable decline and proceed from one stage to the next. For example, a patient in NYHA class IV, Stage C may undergo heart valve replacement surgery and then may have NYHA class II symptoms and be in Stage A post-recovery.

End of life. The Canadian Institute for Health Information (CIHI) (2007) indicates that EOL can be estimated based upon the four main types of EOL trajectories that exist. These trajectories include sudden death, terminal illness, organ failure, and frailty (Lunney, Lynn, & Hogan, 2002). In BC, the Ministry of Health (2013) developed an EOL action plan that defines palliative care and EOL care but not the term *end of life* specifically. The action plan defines EOL care as "care [that is] associated with advanced, life-limiting illnesses, and focuses on comfort, quality of life, respect for personal health care treatment decisions, support for the family, psychological, and spiritual *concerns*" (BC Ministry of Health, 2013, p. 2). The National Institute on Aging (NIA) (2017) defines *end of life care* as "support and medical care given [during] the time surrounding death [however] such care does not happen only in the moments before breathing ceases and the heart stops beating" (para. 2). Of importance when determining which patients with HF are at EOL and are requiring EOL care, the American Heart Association (AHA, 2017) defines this stage as *advanced heart failure*. This advanced stage is when there is little or no symptom improvement despite typical HF therapies including lifestyle restrictions, and when symptoms are occurring with no exertion (AHA, 2017). Thus by recognizing the signs of advanced HF, NPs can better understand when collaboration is needed to provide care at EOL.

The meaning of EOL can be interpreted in several ways, which may pose challenges for NPs trying to collaborate with palliative care teams. The term *end of life* is often used synonymously with *end of life care* although particularly when and how this transition occurs in HF is not well-known. Nevertheless, both terms signify a pivotal stage in life for the patient with HF as palliative care is beneficial to supporting the patient's needs, preferences, and wishes.

If the term EOL is not fully understood by NPs, then there may be difficulty specifically deciding how to implement EOL care for patients with HF. Misunderstandings regarding EOL may be a barrier to accessing and implementing resources used to guide HF care during EOL in the primary care setting. End of life care has been described by the Canadian Hospice Palliative Care Association (CHPCA) (2013) as existing on the end of an illness continuum that begins with an acute stage, leads to a chronic state, and then approaches the end of the continuum. The CHPCA (2013) describes that EOL care encompasses advanced illness and is life threatening. For the purposes of this paper, EOL will be defined using the CHPCA definition of EOL care as it describes this type of care occurring along a continuum rather than during a fixed state, which is a reflection of how patients with HF experience this stage.

Palliative care. The World Health Organization (WHO) (2016) defines palliative care as "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness" (para. 1). Further, the WHO (2016) indicates that palliative care is a means to relieve suffering through "early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (para.

1). The Canadian Society of Palliative Care Physicians (CSPCP) (2016) indicates that palliative care "includes, but is not limited to end-of-life care" (p. 6). Similarly, the CHPCA (2016) defines palliative care as "a special kind of healthcare for individuals and families who are living with a life-limiting illness that is usually at an advanced stage" (para. 1). The CHPCA (2016) indicates that palliative care services are particularly advantageous to implement early in a disease trajectory (2016).

In the context of this paper, the term palliative care will be defined using the CHPCA definition of palliative care as this definition provides a clear indication when to initiate care (i.e. early in the disease trajectory), for whom (i.e. patients with a life-limiting illness) and for what type of care to provide (i.e. pain and symptom management). As palliative care and hospice palliative care *both* encompass a vast spectrum of early-initiated care that aims to provide holistic enhanced QoL for patients and families facing a life-threatening condition, both terms will be used interchangeably in this paper (CHPCA, 2013).

According to Murray, Kendall, Boyd, and Sheikh (2005), the main goal of palliative care is to enhance QoL in preparation for a death that meets the spiritual, psychological and social needs of the person. Palliative care is thus *continuously* provided along a continuum of life-threatening illness. In comparison, EOL care is provided during the *end* of an illness continuum although is still part of palliative care. There are commonalities that exist between both palliative care and EOL care and the main distinguishing factor is invariably *time*. Palliative care can exist at any point in time during the course of HF illness while EOL is associated with a particular point in time in HF, likely the point at which death is nearing.

According to the CHPCA (2017), the origins of palliative care date back to the fourth century in Europe when Christians cared for sick people. The term *palliative care* originated in the 1960's and became associated with the notion of EOL (Lanken et al., 2008). Dr. Balfour Mount, a Canadian physician, was the first to coin the term *palliative care* in 1974, which denoted providing treatment to alleviate symptoms for dying patients (Feldberg, Ladd-Taylor, & Li, 2003; Ottawa Citizen) (as cited in Lutz, 2011). Dr. Mount, the forefather of palliative care in Canada, in 1973 arranged a seminar based on Elizabeth Kubler-Ross's book *On Death and Dying* (Kimel et al., 2014). It was during this time that Dr. Mount identified the gap in knowledge about care for the dying (Kimel et al., 2014). From there, Dr. Mount organized a pilot project in Montreal that featured the first inpatient consultation palliative program alongside a patient ward and a follow-up grief and mourning program (Kimel et al., 2014). Dr. Mount's work was revolutionary, considered to have transformed the care of the dying and was also considered paramount in highlighting the need for care that optimizes QoL (Kimel et al., 2014).

The term *hospice* evolved from the Latin *Hospes* that denoted traveller; this movement saw homes established to care for the dying (Robbins, 1983) (as cited in Lutz, 2011). The terms *hospice* and *palliative care* both convey the same standards of practice (CHPCA, 2013). As a result, the term *hospice palliative care* was developed in the 1970's to acknowledge the union of the terms (CHPCA, 2013). Hospice palliative care recognizes that ideas, beliefs, and attitudes surrounding illness and death are constantly changing and encompass a wide spectrum of adaptation (CHPCA, 2013). The CHPCA (2013) indicates that there was a long-standing belief that hospice palliative care need only be implemented in the few weeks leading up to death, although this belief has since changed. Hospice palliative care has evolved in recent times to encompass the entire spectrum of illness, not just the immediate period just prior to death (CHPCA, 2013). *Hospice palliative care* has been defined by the CHPCA (2013) as "aim[ing] to relieve suffering and improve the quality of living and dying" (p. 6). As communication and decision-making are central to palliative care and given both patients and families are considered integral in this process, they are both included in the concept of palliative care (Goodlin, 2009).

Many terms have been used interchangeably with palliative care, which creates misunderstandings for primary care providers regarding the meaning of palliative care (Hui et al., 2012). For example, the terms EOL care, care of the dying, and terminal care has been used synonymously with palliative care. Misunderstanding regarding palliative care service, like confusion regarding EOL, is a barrier to NP implementation of resources to provide patients who have HF with EOL care. It is therefore imperative to distinguish between EOL and palliative care for patients with HF as the two terms have different meanings.

Nurse practitioners. As primary care providers, NPs are registered nurses (RNs) with advanced education and training that allows them to diagnose and treat and array of health conditions, order diagnostics, and prescribe medications (Canadian Nurses Association [CNA], 2011). Regulation for NP practice in BC was initiated in 2005 (College of Registered Nurses of British Columbia [CRNBC], 2016). Using a holistic approach NPs can practice in a variety of settings, which includes community care, long-term care, hospitals, and NP-led clinics (CRNBC, 2016; CNA, 2016). Nurse practitioners incorporate patient decision-making into care, increase access to primary care, lessen system-based pressures, are considered well-valued, and provide exceptional chronic disease management (CNA, 2016). Fundamentally, NPs consolidate medical diagnoses and treatment with nursing-based principles and standards (CNA, 2016). Interprofessional collaboration is patient-centered (CRNBC, 2017a) and is an NP competency that occurs throughout all levels of care provision.

Primary care. It is important to distinguish primary care from primary health care as the two concepts are often used interchangeably but are actually two different concepts with differing meanings (Muldoon, Hogg, & Levitt, 2006). To delineate between the two, primary care can be thought of as the service provided by primary care providers while primary health care involves patient care in relation to public system functions (Muldoon et al., 2006). Primary care does not include the system functions of health care (Muldoon et al., 2006). The Government of Canada (GOC, 2012) defines *primary care* as "the element within primary health care that focuses on health care services, including health promotion, illness and injury prevention, and the diagnosis and treatment of illness and injury" (para. 1). Thus primary care is concerned with all factors that impact health including level of education, income, housing, and the environment (GOC, 2012).

Within Canada, primary health care serves to provide the delivery of care through initial contact providers including general practitioners, NPs, and pharmacists (GOC, 2012). Many patients with HF are managed within primary care, an aspect of primary health care. For the purposes of this discussion, primary care will refer to an ongoing and comprehensive provision of care by a primary care provider while primary health care will refer to care provided in the context of health systems (Muldoon et al., 2006).

Palliative care team. Specific members of the palliative care team vary depending on the care needs of each individual patient. In terms of care delivery, the CHPCA (2013) indicates that hospice palliative care is "most effectively delivered by an inter-professional team of healthcare providers who are both knowledgeable and skilled in all aspects of care within their discipline of practice" (p. 7). Additionally, Fendler, Swetz, & Allen (2015) indicate that the components of the palliative care team consist mainly of primary care, cardiology, and palliative care in addition to patients and their caregivers.

Individual health care members mentioned in the literature have specifically identified physicians, advanced care providers, and RNs (Fendler, et al., 2015) highlighting that there is a lack of mention of the NP role on the palliative care team. Nurse practitioners may guide HF care throughout the entire course of the illness. As NPs coordinate EOL care needs for patients with HF as the primary care provider, the role of the NP on the HF palliative care team is needed. In regards to this paper, the members of the palliative care team for patients with HF at EOL will include NPs, physicians, specialists, RNs, allied health services, patients, their family members, and caregivers as these are the typical team members involved in providing HF care.

Collaboration. Providing patients who have HF with EOL care requires collaboration. *Collaboration* has been defined as "the situation of two or more people working together to create or achieve the same thing" (Collaboration, 2016). According to the WHO (2010) and on a global scale, *collaborative practice* is when "multiple health workers from different professional backgrounds provide comprehensive services by working with patients, their families, carers, and communities" (p. 13) to coordinate effective care throughout all practice settings.

According to Buckman, Byock, & Fry (2000) communication is considered the most crucial component of providing effective patient-centered care (as cited in Albert, Davis, & Young, 2002). It has been noted that communication can enhance patient-family care satisfaction and support overall patient compliance (Albert et al., 2002). To build from this, the Canadian Interprofessional Health Collaborative (CIHC) (2010) identifies that the underpinnings of patient-centered care include collaborative practice. Interprofessional collaboration has been defined by the CIHC (2010) as "a partnership between a team of healthcare providers and a client in a participatory, collaborative, and coordinated approach to shared-decision making around health and social issues" (p. 24). To develop this partnership, the CIHC (2010) indicates that collaborative leadership, role clarification, team functioning, and interprofessional conflict resolution be taken into consideration. Hence, collaboration is not only considered a means of communication but is also a partnered approach. The CIHC framework (2010) will form the basis of the discussion of this project by focusing on the factors involved that NPs can use to achieve interprofessional collaboration and provide patients who have HF with EOL care.

The Model of Palliative Care

The model of palliative care in Canada has evolved over time to one that now encompass measures that should be implemented early in the course of the illness trajectory versus just prior to death. Advances in health care have also led to longer life expectancies which focus attention on chronic illness and life-limiting disease management (GOC, 2016). The pain and suffering that patients who are palliative experience in the time leading to death, whether days or years, sought the need to establish a palliative care approach that was not localized to hospitals but was extended to the community where the patient could chose to die at home (GOC, 2016). Also, HF illness trajectories and palliative care in Canada have evolved from a transition model to a trajectory model of care as shown in Figure 1 (Murray et al., 2005). To date, neither Canada, nor the provinces or territories have established palliative care strategies or policies in place to help guide palliative care goals for the population as a whole (GOC, 2016).

Nurse practitioners provide care to patients with HF at different points in the disease trajectory and can provide EOL care in the primary care setting. Therefore NPs are essential in the provision of palliative care for patients with HF particularly at EOL and should play a notable role on palliative care teams.

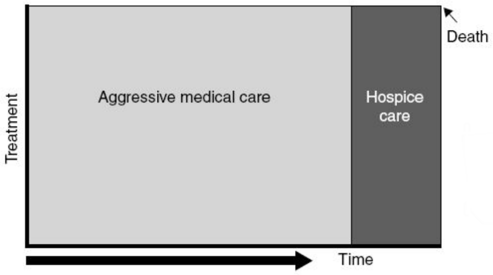

Figure 1a. Transition Model of Care.

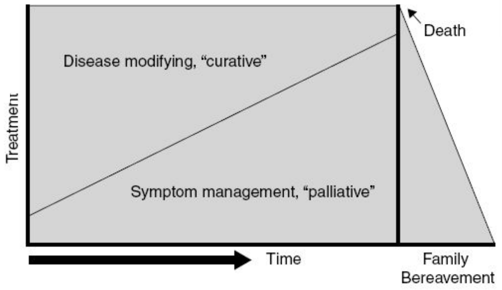

Figure 1b. Trajectory Model of Care.

Note. Adapted from Lynn and Adamson, 2003. With permission from RAND Corporation, Santa Monica, California, USA

Team Management of HF

A multidisciplinary approach is needed for the care of patients with HF at EOL. This is exemplified by McAlister et al. (2004) that found a multidisciplinary approach to HF resulted in a reduction in mortality (risk ratio [RR] 0.75, 95% confidence interval [CI] 0.59 to 0.96), and hospitalization for HF exacerbation (RR 0.74, 95% CI 0.63 to 0.87) compared to controls. Recognition of the importance of multidisciplinary team collaboration in managing HF came about as poor patient health outcomes were found to be apparent with primarily a pharmacological approach to treatment (MacIntyre et al., 2000). A multidisciplinary approach means general practitioners, NPs, RNs, internists, cardiologists, specialty nurses, pharmacists, physical therapists, psychologists or social workers, and dieticians may work together as part of a team approach in managing HF, depending on the needs of the patient (Jaarsma, 2005).

In 2009, a BC provincial strategy led by Cardiac Services BC was initiated, the BC Heart Failure Network, which sought to improve HF care across BC within all health authorities (2016). The BC Heart Failure Network aims to promote collaboration amongst all other BC health authority regions in terms of developing HF quality indicators, patient and provider care resources, educational support, research and guidance (2016).

Palliative care referrals. As part of a multidisciplinary collaboration, palliative care referrals should be initiated to provide patients who have HF with EOL care. Collaboration with the palliative team is necessary as palliative care interventions have been shown to reduce symptom burden and enhance QoL during EOL (Gomes, Calanzani, Curiale, McCrone, & Higginson, 2013). Despite these known benefits, HF referrals to palliative care continue to be very small in number (Wordingham et al., 2016). A systematic HF approach to care has shown to have better patient outcomes, improved QoL, more follow-up, and improved mortality rates (Jaarsma, 2005). Therefore adding a specialty palliative approach to HF may also improve care. For this reason, NPs in primary care should be responsible for coordinating this multidisciplinary approach for their patients with HF, particularly as patients develop to an advanced stage of HF.

Unpredictable Disease Trajectory

Heart failure has an unpredictable disease trajectory as illustrated in Figure 2 (Hupcey et al., 2009). The care management of HF is challenging to coordinate despite the availability of HF guidelines to direct care through worsening and progressive stages (Wordingham et al., 2016). Because of these care management challenges, Murray et al. (2002) indicate that HF management for patients at a worsening point in the disease is not ideal. Additionally, HF prognostication can be difficult to estimate as some patients will recover from an exacerbation and some will not and subsequently become deceased. Thus for primary care NPs, recognizing when patients with HF are nearing EOL may be difficult possibly leading to missed opportunities to provide the benefit of palliative care when needed.

Curative-restorative care versus palliative care. Historically, a curative-restorative care approach to illness management is typically employed and then exhausted before palliative care is implemented (Lanken et al., 2008). Alternatively, another approach indicated by Lanken et al. (2008) includes an interrelated model of curative-restorative and palliative care that outlines that an increasing amount of palliative intervention corresponds with a reduction in curative-restorative intervention. The most ideal, Lanken et al. (2008) suggests a combined model by which a patient would receive a palliative approach *alongside* a curative-restorative approach.

There is a misconception regarding the care that is delivered during palliative care; there is a common thought that treatments to delay the progression of illness cease (Health Quality Ontario, 2016). An approach to palliative care, on the other hand includes the need for the approach to be early, including treatment to improve the QoL for the patient for the duration of the illness (Zimmerman et al., 2014). Palliation should not be considered solely transitional care (Figure 1a) as predicting the HF disease trajectory and mortality is challenging (Albert et al., 2002). Hence to provide the most optimal holistic care, the need for palliative care should be recognized by the NP at the point of diagnosis and should be discussed with the patient to align patient wishes and values with the illness trajectory (Figure 1b and Figure 2).

Palliative care referral timing. Nurse practitioners should identify the optimal timing to collaborate with palliative care teams to support patients with HF in receiving the benefit of palliative EOL care. There are three phases in HF according to Jaarsma et al. (2009). Stage I consists of chronic disease management that is typical of NYHA I-III and includes symptom control and monitoring; Stage II is considered the palliative and supportive stage whereby a patient may need inpatient care and the patient may be showing signs of NYHA III-IV; and Stage III, which is considered the terminal phase (Jaarsma et al., 2009). Both Stage II and III correspond with the ACC/AHA Stage C/D. Thus Stage II is a prime point at which palliative care could be implemented, a point at which goals of care could be realigned to optimize symptom management and QoL (Jaarsma et al., 2009). For the purposes of this paper, the process of palliative care in HF should begin once care providers recognize the patient is ACC/AHA Stage C and experiencing NYHA Class III symptoms.

Prognostication of Heart Failure

The survival rate in HF is estimated to be 66% in the first year, 50% over the course of two years, and 35% over a span of five years (Kimel et al., 2014). Despite the high mortality rate, palliative care measures are underutilized for patients with HF (Jaarsma et al., 2009; Kaasalainen et al., 2011). Kimel et al. (2014) state that the reason for this care underutilization in HF in comparison to other life-threatening conditions is because “prognostication is much less reliable for HF” (Kimel et al., 2014, p. 225).

There are several prognostic tools available in HF (McKelvie et al., 2011). The Seattle Heart Failure Model (SHFM) is one example of a prognostic tool that can be used by care providers (McKelvie et al., 2011). Kimel et al. (2014) indicate that even though prognostication tools are available, they should not replace the value of clinical judgement. Despite knowing that prognostication in HF is challenging, the focus should be on symptom management early in the HF disease process (Kimel et al., 2014). Care providers should recognize that patients with HF whom have comorbidities, several symptoms, reduced QoL, and/or psychosocial issues need to be referred to palliative care (Kimel et al., 2014).

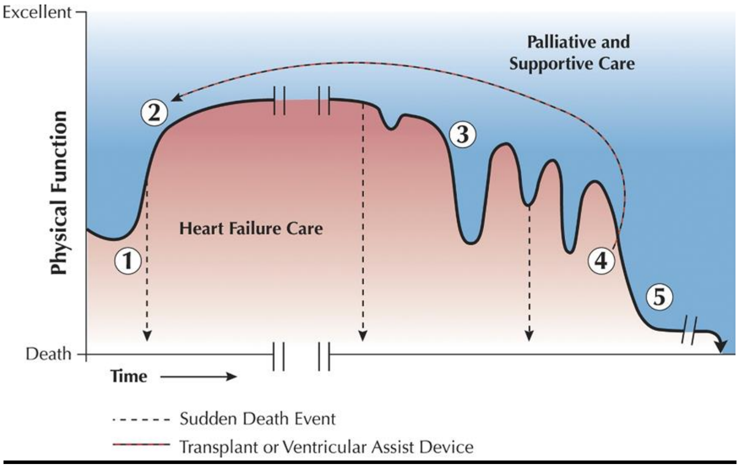

Figure 2. Heart failure illness trajectory.

Phase ① - Initial symptoms of heart failure develop and heart failure treatment is initiated
Phase ② - Plateau of variable length reached with initial medical management, or following mechanical support or heart transplant
Phase ③ - Functional status declines with variable slope; intermittent exacerbations of heart failure that respond to rescue efforts
Phase ④ - Stage D heart failure, with refractory symptoms and limited function
Phase ⑤ - End of life

Dotted lines represent sudden cardiac death that can occur anytime during the trajectory.

Note. Reprinted from Goodlin, S. J. (2009). With permission from The Canadian Care Network.

Lack of Consensus Regarding the Definition of Palliative Care in HF

To provide patients with EOL care, NPs should have an understanding of the meaning of palliative care in HF when collaborating with palliative teams. As there are several ways to describe progressive worsening in HF including *advanced HF, end-stage HF,* and *EOL in HF*, the literature is often unclear in specifically describing when these stages occur. Differing views on the end stages of HF further complicate matters for care providers trying to decide when to provide patients who have HF with EOL care. Further making accessing palliative care difficult is the lack of services that target palliative care for HF populations (Hupcey et al., 2009). To highlight this issue, Pantilat & Steimle (2004) indicate that although palliative care has been identified as an essential component to overall HF management, it has been reported that less than 10% of patients with HF *receive* palliative care intervention. A common misunderstanding among care providers is that palliative care is exclusively for those patients immediately prior to death, which may account for an often untimely palliative care transition (Ward, 2002).

There has been only a limited number of pilot studies completed to date that have evaluated multidisciplinary palliative care along the HF continuum due in part to a lack of consensus regarding the meaning of EOL in HF (Fendler et al., 2015). There also appears to be a lack of consensus specifically regarding when and where to initiate palliative care services aside from the notion that early intervention is essential (Fendler et al., 2015). The lack of clarity regarding the meaning of EOL in HF and an absence of clear indications for palliative referral are barriers to patients receiving palliative care management.

Lack of Communication

In practice, care providers tend to refrain from using the term *heart failure* when discussing the condition with their patients (Murray, Boyd, Sheikh, Thomas, & Higginson, 2004). Thus patients may not truly be informed that they have HF which leads to misunderstandings regarding the diagnosis (Barnes et al., 2006). Barnes et al. (2006) found that impaired communication about HF between the patient and the primary care provider often stemmed from challenges with accurately diagnosing the condition, prognostic uncertainty, fear of eliciting patient anxiety, and difficulties with conveying this information back to the patient in understandable terms. Undermining a true understanding of the condition, the study showed that health care providers would tend to avoid using the term *heart failure* and would instead use euphemisms to describe the condition or would describe HF in terms of symptoms (Barnes et al., 2006).

General practitioners recruited reported they felt more disruption in communication particularly around diagnosis and prognostication of HF when there was an increase in the number of care providers involved in the care management of patients (Barnes et al., 2006). To enhance patient understanding of their HF condition, perceived disruption in communication thus requires role clarification of the multidisciplinary team members individually. Communication is considerably important amongst all multidisciplinary team members involved in caring for patients with HF at EOL and needs to be delivered effectively to convey the care needs of the patient.

Summary

Palliative care should be provided early in the HF illness trajectory instead of just prior to death. Planning for EOL care in Canada continues to be uncommon (Fowler & Hammer, 2013) and there are also many challenges that providers face in the provision of care for patients with HF at EOL. First, the HF illness trajectory is one that is typically not well predicted. This uncertainty paired with limited prognostication makes it difficult to identify if a patient with HF is nearing EOL, which hinders planning for this stage. Also, EOL is just one small aspect of palliative care (CHPCA, 2013) although defining EOL and palliative care in the context of HF continues to be problematic. Second, referrals to palliative care are low for patients with HF as well as referrals to HF clinics, an area of service more likely to implement palliative care measures. Most patients with HF can be managed by general practitioners unless the patient is experiencing a high symptom burden (Kimel et al., 2014). This is an indication that the primary care environment is an ideal place for NPs to manage patients who have HF with prompt recognition of patient decline and early palliative care service referral. Third, lack of communication between care providers, their patients, and families complicates needed discussions regarding HF at EOL. It is therefore important to explore how NPs working in a primary care setting can collaborate with palliative care teams to provide EOL care for patients with HF because of the unpredictable HF disease trajectory, a lack of prognostication, a lack of consensus that defines palliative care in HF, and a lack of communication.

CHAPTER 3

Research Methods

To gather evidence to inform the project question: How can NPs working in a primary care setting collaborate with palliative care teams to provide patients who have HF with EOL care?, a literature search was performed. The Patient, Intervention, and Outcome (PIO) model was used to form the research question and to guide the literature search strategy (Hoffman, Bennett, & Del Mar, 2013). The Cumulative Index of Nursing and Allied Health (CINAHL), PubMed Medline, PsychInfo, Social Work Abstracts, and the National Guideline Clearinghouse databases were searched in December, 2016. Keyword search terms and medical subject headings (MeSH) related to the research question included such terms as: nurse practitioner, family physicians, primary care, collaboration, palliative care teams, end of life, terminally ill patients, heart failure, and ventricular dysfunction (see Tables 1 & 2; Figure 3). In addition to the database search, highly relevant grey literature sources were also retrieved from the BC Heart Failure Network as they were found to be directly applicable to the NP role for palliative EOL care in HF.

Inclusion and Exclusion Criteria

Inclusion and exclusion criteria were developed to identify articles related to the concepts in the research question (see Table 3). Primary care was included as this setting is where NPs may collaborate with palliative care teams to provide EOL care for patients with HF. In Canada, the age of majority varies by province between 18 and 19 years (GOC, 2017). Studies that included youth and children under the age of 19 years were excluded as this group is beyond the scope of this project. Articles written in languages other than English were excluded. Only research studies were included. Finally, date limiters were not chosen to narrow the search as there is limited knowledge on the subject topic and all articles may be useful to inform the research question.

Table 3

Inclusion and Exclusion Criteria of Research Methods Literature Search

Inclusion	**Exclusion**
Nurse Practitioners	Under 19 Years
General Practitioners	Non-English Language
Primary Care Setting	Non-Peer Reviewed Literature
Collaboration	
Palliative Care Teams	
End of Life	
Heart Failure	

Theoretical Framework

A national interprofessional competency framework was developed in 2010 by the CIHC. The CIHC consists of members from different health organizations and includes educators, researchers, health professionals, and students within Canada and is a part of the College of Health Disciplines from the University of British Columbia in Vancouver, Canada (2010). The premise of the framework is the belief that education and collaborative practice with a focus on patient-centered care is fundamental to healthcare team building and will simultaneously improve patient experiences and subsequent outcomes (CIHC, 2010) (see Figure 4). The framework was developed in response to a lack of *interprofessional* competencies that impact patient care in Canada (CIHC, 2010). The first Canadian framework developed to guide interprofessional collaboration, the CIHC (2010) framework can be applied to all health professions. The CIHC (2010) national interprofessional competency framework identifies that the underpinnings of patient-centered care include collaborative practice. Interprofessional collaboration has been defined by the CIHC (2010) as “a partnership between a team of healthcare providers and a client in a participatory, collaborative, and coordinated approach to shared-decision making around health and social issues” (p. 24). To develop this partnership, the CIHC lists four domains that include collaborative leadership, role clarification, team functioning, and interprofessional conflict resolution, that are supported by the domains of interprofessional communication and patient/client/family/community centered-care (2010).

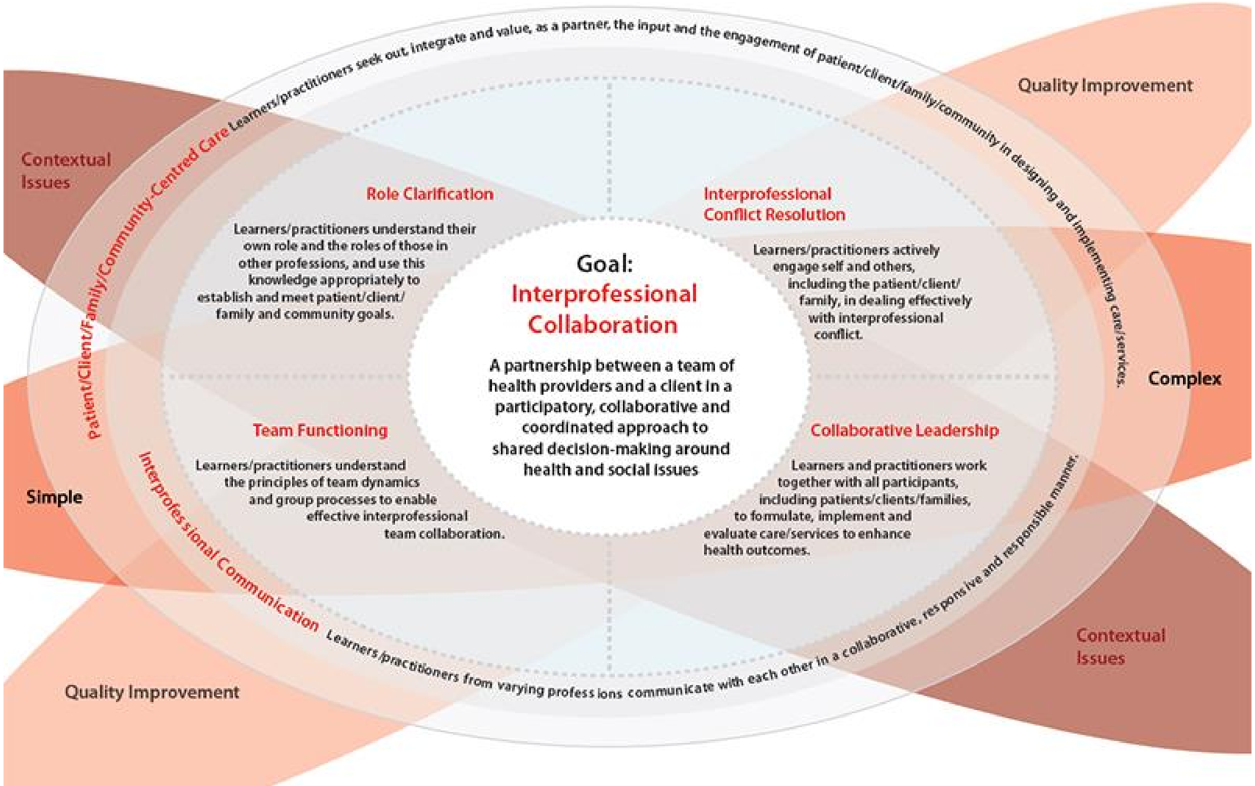

Figure 4. *The National Competency Framework.*

Note. Reprinted from The Canadian Interprofessional Health Collaborative (2017). With permission from John, H. V. Gilbert granted May 23rd, 2017.

Collectively, the six domains of the CIHC framework contribute to effective interprofessional collaboration (2010). Hence, collaboration is not only considered a means of communication but is also a partnered approach. Therefore, the CIHC (2010) national interprofessional competency framework has been chosen for this project as it directly describes the theoretical underpinnings of this paper by outlining the factors involved to achieve interprofessional collaboration.

Levels of Evidence

The level of evidence is the identification of the research design used in the study and is based upon a hierarchical order (Collaborative Center for Integrative Reviews and Evidence Summaries [CCIRES], 2011) (see Table 4). The evidence classification below includes the following levels of evidence that have been used to grade the methodologies of the articles retrieved in the literature search (CCIRES, 2011) for the purpose of identifying what types of evidence currently exist to inform the research question.

Table 4

Levels of Evidence

Level of Evidence	Description
Level A	• Meta-analysis of large or small sample randomized control trials (RCTs) or meta-syntheses of qualitative studies
Level B	• Well-designed controlled studies that includes randomized and non-randomized designs, prospective or retrospective studies, and integrative reviews
Level C	• Qualitative studies, both descriptive or correlational, integrative reviews, systematic reviews, or RCTs with inconsistent results
Level D	• Peer-reviewed professional organization standards; the recommendations are supported by clinically-based studies
Level E	• Case reports, expert opinions, case studies, consensus of experts, and literature reviews
Level MA	• Manufacturers recommendations and anecdotes
Level LR	• Laws and regulations

(Collaborative Center for Integrative Reviews and Evidence Summaries [CCIRES], 2011)

CHAPTER 4

Findings

The CIHC framework posits that collaboration is not solely limited to communication (2010). Collaboration involves “developing and maintaining effective interprofessional working relationships with learners, practitioners, patients/clients/families and communities to enable optimal health outcomes” (CIHC, 2010, p. 8) and is based on the principles of “respect, trust, shared decision-making, and partnerships” (p. 8). For collaboration to occur according to the CIHC framework (2010), the principles of communication, patient/client/family/community centered-care, leadership, role clarification, team functioning, and conflict resolution should be acknowledged in practice. In the context of the CIHC framework, NPs can apply these principles to understand how to collaborate with palliative care teams for patients with HF at EOL.

The final search of the literature resulted in a total of 33 articles (see Figure 3). The majority of the evidence was level C (n=23), given most of the studies were methodologically similar and utilized a qualitative design, followed by level E evidence (n=8). Specifically the levels of evidence included: a level A systematic review and meta-analysis combined study (n=1), level B and C prospective cohort studies (n=2), level C guidelines (n=3), level C systematic reviews (n=2), a level C retrospective cohort study (n=1), a level C pilot study (n=1), level C descriptive designs (n=14), level C and E literature reviews (n= 6), a level E scientific statement (n=1), a level E consensus conference (n=1), and a level E case report (n=1) (see Appendix A). The majority of the literary evidence was found to have taken place in the United States (U. S.) (n=19) and the United Kingdom (U. K.) (n=6). Two articles and one guideline were published in Canada and four articles were published in Australia, Belgium, Germany, and Sweden respectively. The three guidelines and the scientific statement were published between

2011 and 2013. Eight of the articles were published between 2002 and 2007. Twenty two articles were published between 2008 and 2017. Regional grey literature EOL tools recommended from the BC Heart Failure Network, to guide BC care providers in managing EOL care for patients with HF, were also included as the content was considered highly relevant to the research question. Based on the literature retrieved, factors that NPs can use and should address to achieve collaboration with palliative care teams were grouped according to the domains of the CIHC framework (2010) (see Appendix B).

To collaborate with palliative care teams, NPs should recognize the barriers to EOL care for patients with HF. Although collaboration in healthcare aims to improve health outcomes (CIHC, 2010), NPs need to identify barriers to EOL care that may prevent patients with HF from receiving care that reflects the patient's preferences, values, and wishes. Of the 33 articles retrieved, 19 articles identified barriers to receiving EOL care for patients with HF. These barriers include lack of communication, challenges with the ability to predict the HF disease trajectory, uncertainty regarding management decisions, and uncertainties about the referral process to palliative care. Nurse practitioners can provide EOL care for their patients with HF by addressing the barriers to EOL care through working collaboratively with palliative care teams.

In review of the findings, there was little mention of NPs as the primary provider for patients with HF at EOL. Instead, the literature discussed primary care physicians providing such care. While there is a gap in the literature that describes the NP role for patients with HF at EOL, in practice, NPs do provide care to patients with HF at EOL. Therefore, it is reasonable to analyze the research findings from a primary care provider perspective and apply the findings to both primary care physicians and NPs. Even so, despite findings that suggest how physicians can collaborate with palliative care teams for patients with HF at EOL, the literature that describes this process is not clear.

Interprofessional Communication

Interprofessional communication is an essential component of interdisciplinary collaboration (CIHC, 2010). Without clear communication, NPs may have difficulty collaborating with palliative care teams to provide their patients who have HF with EOL care. Thus NPs need to understand that a lack of communication has been found to be a common barrier to EOL care for patients with HF (Appendix B). Literature shows that amongst study participants, there was confusion regarding which specific palliative team member would be fulfilling a particular role in the palliative care planning for patients with HF at EOL (Wotton et al., 2005). In particular, there was a lack of communication regarding the overall coordination of palliative care (Wotton et al., 2005). Like Wotton et al. (2005), Lewis & Stephens (2005) also found that overall a lack of communication played a notable role in preventing optimal palliative care for patients with HF at EOL.

Further, Kaasalainen et al. (2011) found that poor communication between clinicians was a barrier to successful collaborative efforts in managing the care of patients with HF at EOL. This can be exemplified by a pharmacist in the study stating “we’re trying to encourage the physician to communicate with the pharmacist via the prescription, I’ve had patients try to reorder medications that the doctors had intended to stop” (Kaasalainen et al., 2011, p. 47). Poor communication was also experienced between patient participants and their care providers (Kaasalainen et al., 2011). This lack of communication is reflected in the statement, “I guess the doctors were telling me there wasn’t much they could do…but just the other day I was at the heart clinic and they said there were still things they could do for me” (Kaasalainen et al., 2011,

p. 50). Gaps in informed consent and poor understanding of the HF disease trajectory and prognosis were found to be the result of poor communication (Rogers et al., 2000; Murray et al., 2002) (as cited in Lewis & Stephens, 2005). Overall, a common finding was that an insufficient amount of information was relayed to palliative patients with HF (Aldred et al., 2005; Dougherty et al., 2007; Horne & Payne, 2004; Murray et al., 2002) (as cited in Hopp et al., 2010). Consequently, the experiences of patients with HF collaborating with the health care system were found to be inadequate during EOL (Hopp et al., 2010).

Patients may struggle between trying to preserve their longevity and trying to accept a palliative label (Kaasalainen et al., 2011). Similarly, resistance to embrace palliative care has also occurred amongst family members and was found to be due to a reluctance to accept their loved one would be facing death (Kaasalainen et al., 2011). Unpredictability in the HF disease trajectory can lead to patient misunderstandings regarding their health status at EOL (Kaasalainen et al., 2011). Patient misunderstandings are particularly evident when there is a mismatch between how the patient feels and an advanced HF prognosis (Kaasalainen et al., 2011). For example, given the unpredictable trajectory in HF, a patient may have an improvement in symptoms and still be considered to be in an advanced stage of HF. Thus if patients do not have a firm understanding regarding their HF prognosis, collaboration may be difficult to achieve. Findings also show that patients who decline palliative care service did so often as a result of a lack of understanding for or a failure to acknowledge the need for the transition to palliative care service (Kaasalainen et al., 2011). Therefore to promote collaboration, NPs should communicate with patients and resolve misunderstandings so patients with HF can receive the benefit of palliative care at EOL. By promoting this partnership with the palliative care team, NPs can support the patient to resume control over their care (CIHC, 2010).

Shared decision-making was found to be an integral aspect of communication for patients with HF at EOL (Allen et al., 2012). Davidson et al. (2004) discussed The St. George Heart Failure Model that included collaborative palliative care. To address poor communication, Davidson et al. (2004) attributed successful palliative care services as being very willing to provide "education, mentorship, and expert consultancy when required" (p. 72). Anticipation, timing, and review have been identified as communication techniques used to facilitate shared-decision making for patients with advanced HF (Allen et al., 2012). For example, an annual heart failure review to discuss goals of care can be used to anticipate health events (Allen et al., 2012). The guideline by McKelvie et al. (2011) gave direction regarding how EOL discussions should be structured for patients with HF. Specifically, two communication tools (McKelvie et al., 2011) were identified that can be used collaboratively by NPs and palliative teams to provide EOL care: the Assessing Patient Readiness for EOL Discussions and the Framework for Conducting EOL Discussions with HF Patients (McKelvie et al., 2011). The communication tools can provide NPs with an opportunity to collaboratively engage in EOL conversations with patients with HF while also promoting a patient-centered approach to EOL care.

Collectively, the findings show that poor communication adversely affects the care of patients with HF at EOL (Davidson et al., 2004; Lewis & Stephens, 2005; Wotton et al., 2005; Hopp et al., 2010; Kaasalainen et al., 2011) (Appendix B). Poor communication was noted amongst healthcare systems, between clinicians, and through patient interactions. There was no evidence to suggest how NPs in particular can resolve issues with communication that prevents collaboration for patients with HF at EOL. Nurse practitioners should understand that barriers to communication may prevent collaboration from occurring. It should be said that collaboration can still occur between palliative team members even when communication is considered poor.

Effective communication between palliative team members benefits patients with HF by facilitating a team understanding of patient care goals and through promoting collective decision making and responsibility (CIHC, 2010) during EOL.

Leadership

Leadership supports the process of collaboration (CIHC, 2010). Nurse practitioners should take leadership to address challenges with predicting the HF trajectory, initiate palliative care referrals, and initiate advance care planning (ACP) (Appendix C) to provide EOL care for patients with HF. Predicting the HF disease trajectory, initiating palliative referrals and initiating ACP were found in the literature (Seamark, Ryan, Smallwood, & Gilbert, 2002; Hanratty et al., 2002; Goodlin et al., 2004; Lewis & Stephens, 2005; Gott et al., 2007; Hauptman, Swindle, Hussain, Biener, & Burroughs, 2008; Boyd et al., 2009; Beckelman et al., 2011; LeMond & Allen, 2011; Kaasalainen et al., 2011; McKelvie et al., 2011; Allen et al., 2012; Dev, Abernethy, Rogers, & Connor, 2012; Michigan Quality Improvement Consortium, 2012; De Vleminck et al., 2014; Dunlay et al., 2014; Evangelista et al., 2014a; Evangelista, Liao, Motie, De Michelis, & Lombardo, 2014b; Gadoud et al., 2014; Kavalieratos et al., 2014; Fendler et al., 2015; Afshar, Geiger, Muller-Mundt, Bleidorn, & Schneider, 2016; Chandar et al., 2016).

Challenges with the ability to predict the HF disease trajectory. Missed opportunities for collaboration with palliative teams may occur if NPs have difficulty predicting prognoses for their patients with HF at EOL. In the findings, primary care providers identified an inability to accurately predict when patients with HF reached EOL or were near death (Hanratty et al., 2002; Seamark et al., 2002; Goodlin et al., 2004; Lewis & Stephens, 2005; Gott et al., 2007; Hauptman et al., 2008; Boyd et al., 2009; Kaasalainen et al., 2011; McKelvie et al., 2011; De Vleminck et al., 2014; Kavalieratos, et al., 2014). To address the challenges with predicting prognosis, prognostication tools were identified in the literature for patients with HF at EOL (McKelvie et al., 2011).

Tools for HF prognostication for patients with HF at EOL include the Enhanced Feedback for Effective Cardiac Treatment (EFFECT) Heart Failure Mortality Prediction, the Seattle Heart Failure Model (SHFM), the Heart Failure survival score (HFSS), and generic tools such as the surprise question, the Palliative Performance Scale (PPS), and the Karnofsky Performance status (McKelvie et al., 2011). To "provide some prognostic guidance" (2011, p. 327) for patients with HF at EOL, NPs should take leadership and consider the use of these tools in practice.

Early referral timing. Findings show that palliative care referral timing is an important aspect in providing EOL care for patients with HF (Bekelman et al., 2011; LeMond & Allen, 2011; Michigan Quality Improvement Consortium, 2012; Evangelista et al., 2014a; Evangelista et al., 2014b; Gadoud et al., 2014; Kavalieratos et al., 2014; Dunlay et al., 2015; Fendler et al., 2015; Afshar et al., 2016). Yet, there is no current consensus that defines the specifics of referrals including *how* this should take place or *when* the timing of palliative care services should occur. Even though early palliative referrals are preferred for patients with HF at EOL, early referrals do not always occur in practice (LeMond & Allen, 2011). The timing of referrals to palliative care for patients with HF is commonly based upon provider preference (LeMond & Allen, 2011), which may postpone the EOL care that patients need. Delayed referrals to palliative care for patients with HF at EOL can be exemplified in a study by Gadoud et al. (2014) whom investigated entry timing for both patients with cancer and patients with HF. Gadoud et al. (2014) found that 30% of patients with HF in the study were not registered for palliative care until one week before dying and that approximately 50% of patients with HF were only registered six weeks before dying (Gadoud et al., 2014). This trend in delayed referrals to palliative care can be further supported by Dunlay et al. (2015) who found clinician participants reported discussing EOL preferences with patients who have HF primarily only when the condition of the patient deteriorated.

Nurse practitioners should take leadership and use the Supportive and Palliative Care Indicators Tool (SPICT) and the Gold Standards Framework (GSF) to collaboratively work with palliative care teams to provide EOL care. The SPICT was identified as a useful tool that can be used by care providers to recognize the need for palliative care in HF because it lists general health and disease indicators to help assess when a palliative approach may be needed (Afshar et al., 2016). The GSF, an approach now utilized worldwide to enhance palliative care, was also identified in the findings as a way to address patient care needs at EOL (Afshar et al., 2016). The GSF also highlights healthcare organizational practices that can be targeted to improve palliative care (Afshar et al., 2016). Although patient characteristics that suggest a palliative approach may be needed for patients with HF (Afshar et al., 2016), there was no literature found that specifically outlines the exact time that palliative care referrals should be initiated.

Initiate advance care planning. Collaboration with the palliative care team occurs during the process of ACP, a time when providers are promoting EOL care that is patient-centered and adapted to meet the needs of the patient (CHPCA, 2010). Nurse practitioners can collaborate with palliative care teams by taking leadership and initiating ACP by sharing and developing a care plan that reflects the patient’s values, and wishes for EOL. While shared-decision making during the process of ACP engages patients to make EOL decisions that suit their preferences, ACP can be used by NPs to collaborate with palliative care teams to tailor the care plan to the patient’s wishes for EOL.

The need for ACP for patients with HF at EOL was found to be a central aspect of EOL care in the literature (McKelvie et al., 2011; Dev et al., 2012; Michigan Quality Improvement Consortium, 2012; Afshar et al., 2016; Chandar et al., 2016) because it is a way to communicate patient preferences. Findings suggest ACP for patients with HF should occur to support patient decision making at EOL (McKelvie et al., 2011; Dev et al., 2012; Chandar et al., 2012; Ahia & Blais, 2014; Afshar et al., 2016) to enhance patient-centered care. Advance care planning is also necessary for EOL planning given the unpredictable disease trajectory in HF (Ahluwalia & Enguidanos, 2015). Further, ACP can "var[y] greatly by subspecialty" (Chandar et al., 2016, p. 5) suggesting that leadership is needed to initiate the process of ACP between a variety of settings.

One aspect of ACP is the development of advance directives (i.e. the living will). Evidence to support advance directives for patients with HF at EOL, comes from the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) (Dev et al., 2012). The SUPPORT trial "provides the most comprehensive summary of advance care planning maneuvers in the advanced HF setting" (Dev et al., 2012, p. 314). Evidence from the trial suggests that to consistently plan for the completion of advance directives, care providers should engage patients and provide them with advantages towards completing the directive (Dev et al., 2012). There was although no recommendation for the use of advance directives in practice for patients with HF specifically at EOL or for collaborative purposes. As patient engagement is collaborative and as patients with HF are members of the palliative team, ACP is a way for NPs to take leadership and collaborate to provide EOL care for patients with HF.

In regards to location, 75% of cardiologists and 84% of primary care providers agreed that ACP should begin in the outpatient setting (Chandar et al., 2016). In comparison to specialty providers who may only see a patient on one occasion, NPs in primary care may see their patients on multiple and successive occasions. Therefore NPs can initiate and discuss patient wishes regarding ACP in primary care.

To collaborate with palliative care teams for patients with HF at EOL and in relation to ACP, NPs can take leadership and initiate the use of the Advanced Heart Failure Personal Action Plan EOL tool and the implantable cardioverter defibrillator (ICD) deactivation clinical practice guideline from the BC Heart Failure Network (2017b). As the BC Heart Failure Network is committed to collaborative practice within BC, the action plan has been specifically developed to be used in practice and shared between the patient and providers caring for patients with HF at EOL (BC Heart Failure Network, 2017a). Specific to both HF and EOL care, these documents are highly relevant to this project as they have been implemented into practice and are currently being utilized by primary care providers, including NPs throughout BC (2017b).

Both the action plan EOL tool and the ICD deactivation guideline can be used specifically for collaboration between NPs and palliative care teams by sharing ACP specific information that will support a standardized palliative team approach towards ACP and overall HF EOL care management (BC Heart Failure Network, 2017d). For example, the personal action plan can be completed together by the patient and the NP to document collaborative decisions for symptom and psychological management as well as the collaborative team approach needed to succeed in meeting those management decisions (BC Heart Failure Network, 2017c). The patient can then share the personal action plan with other members of the palliative care team to convey EOL preferences in regards to ACP, such as during a cardiologist follow-up visit. All members of the palliative care team can utilize the personal action plan by the BC Heart Failure Network

(2017c) to collaborate by promoting a common understanding of the patient's preferences for EOL care.

Role Clarification

Through role clarification, "practitioners understand their own role and the role of others and use this knowledge appropriately to establish and achieve patient/client, family, and community goals" (CIHC, 2010, p. 12). Aspects of role clarification, including identifying team member roles and designating a leadership role to oversee EOL care for patients with HF, were identified in six of the articles (Hanratty et al., 2002; Davidson et al., 2004; Daley, Matthews, & Williams, 2006; Boyd et al., 2009; Fendler et al., 2015; LaDonna et al., 2016) (Appendix B).

Identify the palliative team members. Nurse practitioners may have difficulty providing a coordinated and collaborative approach to HF management at EOL if the specific team members involved are unknown. To facilitate a team-based collaborative approach, team members should be identified because of the complexity of HF care management, particularly during EOL (Fendler et al., 2015). Identification of individual palliative team members is essential as there may be multiple team members with varied levels of training that support patients with HF at EOL in a specific and unique way (Fendler et al., 2015). The term *palliative care team* is well-known in healthcare although an understanding of the individual members that comprise the team remains vague in practice as inclusion may vary between teams.

The patient, the carer, the primary care provider, the palliative care medical specialists, palliative care nursing, occupational therapy, pastoral care, physiotherapy, social workers, and volunteers were identified as part of the palliative care team by Davidson et al. (2004). Additionally, members from day therapy, psychologists, practical nurses, and hospice inpatient caregivers have been identified as other possible individual palliative team members (Daley et al., 2006). A family member or caregiver, a nurse, a family physician or cardiologist, nephrologists to manage advanced renal dysfunction, palliative care specialists, other specialists, pharmacists, and other non-specified allied health professionals have also been identified as members of the palliative care team (LaDonna et al. 2016). Nevertheless, the findings lack clarity for NPs regarding the purpose of the palliative care team member composition and specific role responsibilities for the care of patients with HF at EOL. As collaboration is a central component to a team management approach to HF, organizing role responsibilities should occur to optimize the health outcomes for the patient (CIHC, 2010).

Designate a leadership role. Multiple palliative team members managing patients with HF at EOL can create uncertainties regarding individual team roles (Daley et al., 2006). This can be exemplified in a study that found "one [participant] described how he felt no one 'in authority' was overseeing him, which caused him concern" (Daley et al., 2006, p. 598). In HF disease management, the primary care provider may also refer to other specialities such as cardiology and possibly nephrology (i.e. in cases of progressive renal dysfunction) for HF management assistance that results in a shared approach to care.

Despite the lack of evidence that outlined specific palliative team role responsibilities, the findings suggested "a key professional to coordinate care, provide personalized information and support self-management" (Boyd et al., 2009, p. 770). Similarly, Hanratty et al. (2002) stated "…it should be the physician who's interested [in HF care management], the general practitioner, the district [specialist] nurse" (Hanratty et al., 2002, p. 583). Further, several of the study participants also believed that the general practitioner was the fundamental team member in palliative care for patients with HF (Hanratty et al., 2002). Nurse practitioners can assume a leadership role and facilitate collaboration with the rest of the palliative team because an ideal palliative team leader is a central care provider (Hanratty, 2002; Boyd et al., 2009; Fendler et al., 2015).

Team Functioning

To facilitate effective interprofessional collaboration, team members should "develop a set of principles for working together that respects the ethical values of members" (CIHC, 2010, p. II). Elements of team functioning in the literature were found to include, promoting a holistic perspective and building expertise (Davidson et al., 2004; Diop, Rudolph, Zimmerman, Richter, & Skarf, 2017; Hauptman et al., 2008; Kaasalainen et al., 2011; McKelvie et al., 2011; Yancy et al., 2013; Brännström & Boman, 2014) (see Appendix B).

Use a holistic perspective. A holistic perspective is one that incorporates the physical, psychological, spiritual, and psychosocial aspects into care and strengthens the care provider's awareness of the patient's needs (Zamanzadeh, Jasemi, Valizadeh, Keogh, & Taleghani, 2015). Collaboration contributes towards promoting a holistic perspective for patients with HF at EOL (Kaasalainen et al., 2011) because it helps palliative teams work towards reaching patient goals. This is demonstrated by one nurse describing "[the] need for a good multidisciplinary team that looks at things like function, things in the home, energy-conserving techniques…somebody [patients] can talk to about their fears" (Kaasalainen et al., 2011, p. 47). To support team development practices in achieving multidisciplinary care (Diop et al., 2017; Kaasalainen et al., 2011), NPs should promote a holistic perspective for patients with HF at EOL given a holistic perspective underlies all aspects of the nursing profession (Zamanzadeh et al., 2015).

Findings show that "the studies with improvement in the largest number of outcomes prioritized the integration of interdisciplinary HF and PC [palliative care]" (Diop et., 2017, p. 89). To understand how to provide this all-inclusive care, optimal team functioning requires that team members “share information needed to coordinate care with each other and patients, families, and communities to avoid gaps, redundancies, and errors that impact both effectiveness and efficiency of care delivery” (CIHC, 2010, p. 14).

In the literature it is also suggested that health outcomes for patients with HF at EOL may improve with the combination of primary care HF and palliative team comprehensive care (Diop et al., 2017). Diop et al. (2017) noted QoL outcomes improved by 83%. Brännström and Boman (2014) found a statistical improvement in higher QoL measures from baseline (p=0.02) amongst patients with HF at EOL who were involved in the new model of holistic palliative care, the palliative advanced home care and heart failure care (PREFER) model, in comparison to the control, those who received usual care. The comprehensive, holistic palliative care model proposed by Davidson et al. (2004) posits a multidisciplinary approach to EOL care in HF although there was little description of how to implement the model in practice. Yancy et al. (2013) indicated comprehensive palliative care is of benefit for patients with HF at EOL to improve QoL although there was no specific direction for practice implementation.

Build expertise. Building expertise in EOL care for patients with HF is needed. To support the palliative team in caring for patients with HF at EOL, NPs should build HF symptom management expertise to better provide continuity of care. Despite established recommendations that guide HF in terms of medical treatment, there is a lack of evidence that outlines specific palliative care measures during the EOL period for persons with HF (Kaasalainen et al., 2011). Building expertise was identified by Kaasalainen et al. (2011) as a need in HF management during EOL while McKelvie et al. (2011) outlined symptom management for patients with advanced HF. Care providers should consider that these recommendations have not been formally peer-reviewed. Findings also give direction for the organization of HF care that suggests utilization of the chronic care model (CCM) based on the Canadian Heart Health Strategy and Action Plan (McKelvie et al., 2011).

In the study by Kaasalainen et al. (2011), most of the health professionals reported that further HF expertise was needed to manage patients at EOL. Study participants expressed a “lack of confidence” (p. 46) in the overall treatment for HF, including pharmacological management and technology (i.e. ICD) (Kaasalainen et al., 2011). Nurses and the physicians voiced concern over the multiple numbers of medications that patients with HF are often prescribed at EOL and noted uncertainties surrounding when opioids ideally should be added to the regime (Kaasalainen et al., 2011).

Nurse practitioners can address knowledge deficits in the care of patients with HF at EOL by contributing to the knowledge base regarding pharmacological and technological treatment. In particular, NPs can use the findings by McKelvie et al. (2011) who provides symptom management guidance for practitioners in managing care for patients with HF at EOL. Also, the BC Heart Failure Network EOL tools include clinical practice guidelines for heart failure symptom management that can be used by NPs to build expertise and strengthen team functioning (2017b).

Resolve uncertainties about the referral process to palliative care. Patients with HF may not receive the benefit of palliative care at EOL if uncertainties related to palliative care referrals exist. While palliative referral processes and criteria may differ across health jurisdictions, referrals to EOL care have been found to be relatively uncommon in practice for patients with HF (Hauptman et al., 2008).

Despite identifying these uncertainties regarding the palliative referral process, there was no clear indication that suggests how NPs may resolve this issue. Hauptman et al. (2008) found that 64% of cardiologists, 45% of geriatricians, and 68% of internal medicine physicians and family practice general practitioners were uncertain about the right time to initiate a palliative referral. Further, 47% of cardiologists, 56% of geriatricians, 44% of internal medicine physicians and family practice general practitioners in the study were concerned about their patients with HF not being accepted by palliative care services despite completion of a referral to the team (Hauptman et al., 2008). Thus as a result of uncertainty, NPs may experience challenges collaborating with palliative care teams if the palliative referral process is not clear for patients with HF at EOL. Also, NPs may not refer patients to palliative care if barriers to acceptance are likely to be encountered.

Interprofessional Conflict Resolution

Interprofessional conflict resolution supports "developing a level of consensus among those with differing views; allowing all members to feel their viewpoints have been heard no matter what the outcome" (CIHC, 2010, p. IV). Resolving conflict is thus necessary to achieve successful interprofessional collaboration (CIHC, 2010). Even though conflict is often avoided, conversely team members should "value the potential positive nature of conflict" (CIHC, 2010, p. III). Findings show that conflict can arise when "an intervention desired by a patient may appear discordant with the patient's stated goals and/or medical realities, and clinicians must explain why it is not warranted" (Allen et al., 2012).

In setting goals of care for patients with HF at EOL, a six-step approach identified in the literature includes the identification and resolution of conflict (Ahia & Blais, 2014). One family member stated "Dad has always been a fighter, so we're not giving up. We believe in miracles" (Ahia & Blais, 2014), exemplifying that family may not want to accept an EOL HF prognosis, which may result in conflict within the palliative care team. Nurse practitioners should recognize potential sources of conflict between members of the palliative care team that may prevent collaboration for patients with HF at EOL. Such sources of conflict may be the result of "role ambiguity, power differences, and differences in goals" (CIHC, 2010, p. IV). Ahia and Blais (2014) noted the steps in identifying and resolving conflict. These steps include recognizing the source of the conflict (e.g. gaps in knowledge, uneven treatment goals between physicians, emotionally-related issues, family issues, and grief), focusing on the conflict with the goal to resolve it, and utilizing statements that express empathy (Ahia & Blais, 2014). Although not identified specifically in the case report as part of the medical team, NPs can use the six-step approach outlined in Ahia and Blais (2014) to set goals of care. By setting these goals and identifying and resolving conflicts, the patient's wishes can become aligned with HF medical management (Ahia & Blais, 2014). Conflict may persist between palliative team members although attempts to resolve conflict should be made by NPs to collaborate in providing EOL care for patients with HF.

To improve patient-centered EOL care for patients with HF, NPs can also implement measures suggested by Allen et al. (2012) that focus on conflict resolution. These include: (Allen et al., 2012)

- Emphasizing the therapies the patient is currently receiving relative to how such therapy aligns with their goals of care.
- Addressing the patient's emotional motivation behind the HF management.
- Clarifying any misunderstandings regarding HF therapies.

In summary, barriers and issues related to patients with HF receiving EOL care have been identified. To collaborate with palliative care teams to provide EOL care for patients with HF, ways to address these barriers and issues in the findings can therefore be used by NPs. These ways to collaborate focus on communication, taking leadership, role clarification, promoting team functioning, and conflict resolution.

CHAPTER 5

Discussion

As noted in the literature, many patients with HF at EOL do not receive the palliative care they need (Wotton et al., 2005). For that reason, to provide EOL care that reflects patient preferences, wishes, and values, NPs should work together collaboratively with palliative care teams. Despite recognition that collaboration is needed for patients with HF at EOL, the term collaboration is used loosely and specifics on *how* practitioners should collaborate are lacking in the literature. By utilizing the CIHC framework (2010), NPs can collaborate with palliative team members by optimizing communication, taking leadership, clarifying team roles, optimizing team functioning, and resolving conflict (Appendix C).

Even though the literature does not exclusively focus on communication-based strategies to facilitate collaboration as might be expected, communication is essential to the process of collaboration (CIHC, 2010). There are communication tools specific to HF that can guide NPs in discussing EOL with patients (McKelvie et al., 2010). To resolve misconceptions that may prevent the patient with HF at EOL from receiving palliative care, patient engagement should occur as an aspect of collaborative communication (Appendix C). Additionally, NPs can take leadership to engage and collaborate with palliative care teams. This can be done by utilizing HF prognostication tools to communicate prognosis with patients and other providers, initiating early palliative care referrals, and initiating ACP discussions to communicate patient care preferences for EOL (Appendix C). Moreover, NPs can collaboratively engage in palliative team role clarification by defining and communicating the roles of individual team members and by liaising with the palliative team for leadership and direction (Appendix C).

Furthermore, NPs can collaborate by optimizing palliative team functioning through the implementation of a holistic perspective that incorporates the PREFER model. Nurse practitioners can also build expertise through information sharing with the team and can communicate uncertainties about the referral process to palliative care (Appendix C). Lastly, to resolve conflict that may arise amongst the team, NPs can collaboratively engage in interprofessional conflict resolution by utilizing the six-step approach outlined by Ahia and Blais (2014) and by utilizing the steps towards conflict resolution by Allen et al. (2012) (Appendix C).

Interprofessional Communication

Communicating patient and family needs is integral to establishing holistic patient care in palliative care. Jaarsma, Brons, Kraai, Luttik, & Stromberg (2013) suggested that a multidisciplinary approach to HF occur across the disease trajectory. A multidisciplinary approach may lead to enhanced communication and more consideration given to patient values, a more efficient recognition of referral to specialists, and perceived improvement during EOL for patients with HF (Jaarsma et al., 2013). Additionally, as there is a shortage of specialist palliative care services throughout Canada (CSPCP, 2016), Fendler et al. (2015) have suggested that a *shared-care* multidisciplinary model, one that enhances the stream of care between primary and specialist care, be used for all patients with HF. Lead coordination of the palliative care team at the beginning stages of illness is considered a favourable step in organizing a multidisciplinary approach (Fendler et al., 2015). Communication is required as part of interprofessional collaboration as it supports the principles of team work, conveys an understanding of care decisions, works to encourage trusting relationships, and seeks to efficiently use information with the goal of improving patient health outcomes (CIHC, 2010). Providers can use communication to support collaborative practices by promoting patient/client/family/community-centered care, effective leadership, team functioning, role clarification, and resolution of conflict (CIHC, 2010).

Poor communication within healthcare systems, between clinicians, and between care providers and patients can lead to ineffective collaborative relationships and possible conflict among palliative team members. In review of the literature, ways communication can be used to collaborate for patients with HF at EOL were unclear. Lewis and Stephens (2005) described ineffective communication practices for patients with HF at EOL, although only mention a “multidisciplinary approach” (p. 565) as a potential solution. Additionally, the St. George Heart Failure Model described by Davidson et al., (2004) succeeded as a result of effective communication practices between teams, “in particular the readiness of the palliative care service to provide education, mentorship, and expert consultation when required” (p. 72). However, in this statement by Davidson et al. (2004) it is unclear what the types of communication are used to collaborate.

Patients desire an efficient transition to palliative care when they have been adequately prepared over the course of care provider discussions (Kaasalainen et al., 2011). The guideline identified two communication tools, the Assessing Patient Readiness for EOL Discussions and the Framework for Conducting EOL Discussions with HF Patients that can be used to inform NP practice (McKelvie et al., 2011). Nurse practitioners can also share these tools with the palliative care team for future collaboration with patients with HF. For example, the Assessing Patient Readiness for EOL Discussions tool can be shared by providers on the palliative team and used as a continuous collaborative tool versus on just one occasion. This should be done because patients with HF may choose to discuss EOL periodically as they may not retain large amounts of information. To support patient readiness, the Framework for Conducting EOL Discussions with HF Patients tool can be shared and used between providers, as patients with HF at EOL are likely to have multiple care interactions. Hence, a collaborative approach can be used to guide EOL discussions in a consistent manner with the use of the communication tools identified by McKelvie et al. (2011). It is important that NPs also consider other established palliative EOL tools that focus on communication that may be available.

Lack of communication (Wotton et al., 2005; Lewis and Stephens, 2005; Kaasalainen et al., 2011), confusion (Wotton et al., 2005), and patient misunderstandings (Kaasalainen et al., 2011) were found to impact the collaborative process for patients with HF at EOL. As such, NPs should be consistent with the way they communicate. Communication should guide EOL discussions while also supporting the patient as a member of the team and should be authentic and transparent while conveying respect and trust (CIHC, 2010). Nurse practitioners should also be attentive towards non-verbal cues (CIHC, 2010).

Issues with communication should be addressed by NPs on an ongoing basis during the care of patients with HF at EOL. The CIHC competencies to communicate effectively that can be used by NPs include "establish[ing] teamwork communication principles, actively listen[ing] to [all] team members, communicat[ing] to ensure [a] common understanding of care decisions, develop[ing] trusting relationships, [and] effective[ly] using information and technology" (2010, p. III). An annual HF review recommended by Allen et al. (2012) is a practical example that provides NPs with an opportunity to support communication and collaborative efforts with the palliative team. Although meeting annually to discuss HF EOL care is important in supporting the patient's needs, NPs should arrange for the team to meet more than on an annual basis. Meetings can be arranged to take place quarterly as patients with HF at EOL may experience a high symptom burden (Gadoud et al., 2014); an approach better suited towards addressing ongoing palliative care needs and treating symptoms. Palliative team members could meet via teleconference and an agenda item could focus on the review of communication that occurred amongst the palliative team since the previous meeting. Nurse practitioners should thus recognize that communication is an important consideration to providing patients who have HF with EOL care.

Take Leadership

Address challenges with heart failure prognostication. Difficulties with HF prognostication may result in palliative care referrals occurring too late in the trajectory (Hanratty et al., 2002). Although challenges with HF prognostication are a barrier towards patients with HF receiving EOL palliative care (Hanratty et al., 2002; Goodlin et al., 2004; Lewis & Stephens, 2005; Gott et al., 2007; Hauptman et al., 2008; Kaasalainen et al., 2011; De Vleminick et al., 2014), many of the articles did not indicate how to resolve this issue. Despite a lack of evidence, NPs can take leadership and improve HF prognostication by implementing the tools identified in the literature including the EFFECT Heart Failure Mortality Prediction, the Seattle Heart Failure Model (SHFM), the Heart Failure survival score (HFSS), and generic tools such as the surprise question (i.e. asking oneself if you would be surprised if the patient passed away within the year), the Palliative Performance Scale (PPS), and the Karnofsky Performance Status (McKelvie et al., 2011). By utilizing HF prognostication tools on an ongoing basis, NPs can identify EOL earlier in the HF trajectory and lead the initiation of EOL care.

Both the PPS and the Karnofsky Performance Status (McKelvie et al., 2011) may be used by NPs to evaluate functional limitations for patients although should not be relied upon to assess mortality as these tools are not specific to HF. The EFFECT Heart Failure Mortality Prediction tool is not a clinically appropriate choice for NPs to assess mortality risk from HF in primary care as the tool is indicated for the hospital setting (Canadian Cardiovascular Outcomes Research Team, 2016). The SHFM has been prospectively validated and is considered an accurate tool for estimating one, two, and three-year survival rates (University of Washington, 2015) and thus can be used by NPs in primary care for HF prognostication. While use of the SHFM is a tool to predict HF prognosis, the tool also provides an opportunity for NPs to collaboratively engage with the patient so they have the opportunity to express their specific preferences for treatment during EOL. The surprise question can be used to guide NPs to consider the use of the SHFM. From there, the SHFM score can be utilized by NPs not only for HF prognosis but also collaboratively to communicate prognosis with the patient and when appropriate with palliative team members for transition to EOL care.

In summary, while the surprise question and the SHFM are both useful in guiding NPs with HF prognostication, it is important to consider that the tools lack diagnostic utility for EOL (Levy et al., 2006; White, Kupeli, Vickerstaff, & Stone, 2017). Even in the setting of prognostic uncertainty, NPs can use the available HF prognostic tools and their clinical judgement to guide practice and discussions with patients and the palliative team to predict if the patient is nearing EOL.

Initiate early referral timing. Referrals to palliative care offer NPs the opportunity to collaborate with palliative teams to provide EOL care for patients with HF. Although early palliative care referrals are preferred (LeMond & Allen, 2011), the timing remains vague. There is a lack of evidence that suggests when NPs should initiate referrals to palliative care for patients with HF. An appropriate approach to palliative care referrals is to initiate a discussion with the patient and assess if palliative care aligns with the patient's goals of care. By engaging with the patient, NPs are thus taking leadership and collaborating in shared-decision making.

Nurse practitioners can provide patients who have HF with EOL care by contacting palliative care services early on in the HF disease trajectory for care suggestions and advice. Palliative care referrals should not be initiated if the patient does not envision palliative care as part of their EOL plan. A HF palliative referral should take place prior to a patient reaching the EOL stage as the CHPCA indicates that palliative care services should be implemented early in a disease trajectory (2016b) and given palliative care occurs along an illness continuum.

Indicators that can be used to predict which patients with HF likely benefit from a palliative care assessment include: (BC Heart Failure Network, 2017c)

- Asking: Would one be surprised if the patient were to die in the following six to 12 months?
- A poor performance status (i.e. diminished self-care, unable to leave the bed or chair for most of the day, or deterioration); several hospitalizations within the past six months; more home care that is required or the patient resides in a home care facility; the presence of multiple comorbidities that cause deterioration.
- The presence of two or more of the following: NYHA III-IV as a result of valvular disease or coronary artery disease that cannot be reversed through surgery or angioplasty; continuous breathlessness or chest pain in light of the patient being treated with optimal medication therapy; renal dysfunction with a GFR < 30 ml/min; cachexia; reduction in lean body mass; reduction in muscle strength; anorexia; fatigue and abnormal chemistry values; presence of anemia with a hemoglobin < 115; uric acid > 565; albumin < 32; and two or greater occurrences whereby the patient required intravenous therapy within the past six months (i.e. furosemide and/or inotropes) (BC Heart Failure Network, 2017c).

Stage II HF as outlined by Jaarsma et al. (2009) corresponds with ACC/AHA Stage C/D and NYHA Class III/IV and is the stage at which early referrals to palliative care should be made. Once recognizing when the patient has reached Stage II HF, NPs can educate their patients that this is a preferred time for entry into palliative care (Jaarsma et al., 2009). In practice however, NPs may find recognizing when the patient has reached Stage II HF challenging particularly if the patient does not report worsening symptoms. To avoid the EOL conversation occurring during an acute deterioration of health, NPs should consider initiating the palliative referral prior to the patient requiring inpatient care.

Eligibility criteria for palliative care is a major challenge for NPs trying to collaboratively initiate an early palliative referral during Stage II HF. In practice, palliative care teams in BC often have eligibility criteria that precludes patient acceptance to a palliative care program if life expectancy is more than six months (Northern Health [NH], 2015). If NPs try and refer patients to palliative care early, the referral may be declined if the patient with HF at EOL does not meet the palliative eligibility criteria thereby limiting the ability of initiating the referral early. Another challenge for NPs is that life expectancy of six months or less is required for the patient with HF to become eligible to receive palliative care benefits (BC Ministry of Health [MoH], 2017).

A recent guideline released by the BC Government (2017), The Palliative Care for the Patient with Incurable Cancer or Advanced Disease, indicates that palliative care should be initiated early in the course of advanced disease. While recognizing the need for early palliative care in chronic disease, the guideline does not address the current life expectancy eligibility criteria barrier to access palliative care services that many patients with HF are likely to experience.

Despite the barriers to receiving palliative care as mentioned above, useful practice tools have been identified in the findings that can assist NPs in predicting the need for palliative care in HF and in providing support for entry into a palliative care program. These tools include the SPICT and the GSF (Afshar et al., 2016). The SPICT can be used by NPs “to identify people at risk of deteriorating and dying… for holistic, palliative care needs assessment and care planning” (The University of Edinburgh, 2017, para 1). Of note, Afshar et al. (2016) does not provide specifics for how the SPICT can be practically applied for patients with HF at EOL. Nurse practitioners can refer to the SPICT for patients who may be deteriorating or dying by identifying indicators of worsening health such as patients requiring assistance with personal care, weight loss greater than 5-10%, and a persistence of symptoms despite treatment optimization (The University of Edinburgh, 2017). Nurse practitioners can also refer to the heart and vascular disease section of the tool as a clinical indication for palliative care planning in HF (The University of Edinburgh, 2017). Clinical indicators prompting the NP to initiate the palliative care referral includes the presence of ‘NYHA class III-IV heart failure or extensive, untreatable coronary artery disease; with breathlessness or chest pain at rest or on minimal effort” (The University of Edinburgh, 2017, p. 1). As part of initiating the referral to palliative care, the SPICT also prompts the NP to evaluate the current treatment regimen to optimize medication therapies, to resolve the problem of polypharmacy, to evaluate the need for specialist referral for consistent difficulties with symptom burden, and to collaboratively engage in conversations for patients with HF at EOL and their family regarding the future plan, decision-making, and care coordination (The University of Edinburgh, 2017).

In addition to the SPICT, the GSF was also identified by Afshar et al. (2016) as a clinical tool that providers can use to approach palliative care for patients with HF at EOL. Similarly to the SPICT, Afshar et al. (2016) did not indicate specifically how the GSF should be implemented in practice. Nurse practitioners can utilize the GSF, “a systematic, evidence based approach to optimising care for all patients approaching end of life”, (para. 3, 2017) including enrolling in training programmes to better provide EOL care.

Initiate advance care planning. Advance care planning is needed for patients with HF at EOL (McKelvie et al., 2011; Dev et al., 2012; Michigan Quality Improvement Consortium, 2012; Afshar et al., 2016; Chandar et al., 2016). A lack of ACP practice tools and provider time restraints inhibit ACP discussions for patients with HF at EOL (Chandar et al., 2016). Nurse practitioners can utilize the Advanced Heart Failure Personal Action Plan from the BC Heart Failure Network (2017a) as a tool related to ACP to collaborate with the patient and to record patient preferences for care and decisions related to care (2017a).

Nurse practitioners should consider that even though there was a lack of ACP tools specific to HF in the findings, the BC guideline, My Voice: Expressing My Wishes for Future Health Care Treatment is an ACP document often used in practice for patients with HF during EOL. To collaboratively engage the patient in establishing their goals of care for EOL, NPs should continue to use the My Voice ACP document, in addition to the action plan by the BC Heart Failure Network (2017a). To support the patient’s wishes for EOL, these ACP tools just mentioned should also be shared with the HF palliative care team.

Advance care directives and living wills are forms of ACP that patients may prefer to discuss with NPs in primary care. Nurse practitioners should encourage and plan for ACP discussions given ACP facilitates a patient-centered care focus. Provider time restraints have been found to hinder ACP (Chandar et al., 2016) thus ACP discussions for patients with HF at EOL should be allotted appropriate clinic time and planned for in advance.

Address Role Clarification

Identify the palliative team members. Nurse practitioners should identify and utilize the strengths of each palliative team member. To collaborate, team members “must frequently determine who has the knowledge and skills needed to address the needs of patients/clients to allow for a more appropriate use of practitioners” (CIHC, 2010, p. 12). Although several team members are part of the palliative care team as suggested in the findings (Davidson et al., 2004; Daley et al., 2006; LaDonna et al., 2016), there is little evidence in the literature that describes the NP role as a part of the team. Nurse practitioners should recognize that patients with HF at EOL are also members of the palliative care team. By recognizing the contributions of each role, the team members are collaboratively integrating the expertise of others (CIHC, 2010) to promote a patient-centered focus of care for patients with HF at EOL.

Nurse practitioners should engage with palliative care teams to request a review of current palliative and HF resource documents available in each health authority as part of role clarification. Many palliative and HF resource documents may only refer to physicians providing such care. To reflect that NPs provide primary care to patients with HF at EOL, NPs should request that all health authority-wide documents be updated to include physicians *and* NPs in the terminology if within NP scope of practice.

Designate a leader. Palliative teams designate a leadership role to provide structure and support for the team and to achieve predetermined goals. To promote collaboration, individuals on the palliative team should recognize which members have the capacity and skill to fulfill the needs of the patient and provide insight into the use of practitioner time (CIHC, 2010). Designating a leadership role is therefore needed to coordinate a team approach (Hanratty et al., 2002; Boyd et al., 2009, Fendler et al., 2015) and to oversee the care needs of patients with HF at EOL (Hanratty et al., 2002; Boyd et al., 2009; Fendler et al., 2015).

Patients with HF and their families “highly valued a key health professional in a supportive, continuing relationship with them who could coordinate and plan their care proactively, offer personalized information, and foster self-management” (Boyd et al., 2009, p. 769). There was a lack of literature to suggest how NPs specifically can take a leadership role in overseeing the care needs of patients with HF at EOL. Family physicians were identified as the most ideal team member to be responsible for coordinating EOL care for patients with HF (Hanratty et al, 2002). The literature outlines that once a patient with HF is determined to be at EOL, then the initial lead of the palliative team may be taken by the primary care provider as palliative care may only be required periodically (Fendler et al., 2015). Nurse practitioners are well-suited to assume the leadership role of the palliative team as NPs are autonomous providers (CRNBC, 2017b) and manage the primary care needs for patients with HF from the beginning stage to EOL. Alternatively, according to Fender et al. (2015), it is important to consider that “in end-stage [HF] disease, palliative care specialists might take more central ownership of the patient’s care” (p. 4).

A challenge with this approach for NPs is that they may have difficulty recognizing when the patient is at end-stage HF given the unpredictable disease trajectory. It also remains unclear when the leadership handover should occur with palliative care. Palliative care services in BC are typically consultative therefore palliative care specialists assuming the main care of patients with HF at EOL may not occur. Apart from these challenges in practice for NPs, leadership role clarification regarding care for the patient with HF at EOL provides NPs with an opportunity to collaborate with the palliative team by clarifying leadership.

Promote Team Functioning

Complex care situations, such as EOL care for patients with HF, requires collective planning, strategizing, and problem-solving to optimize care outcomes for the patient (CIHC, 2010). Interprofessional collaboration is thus able to take place when the team understands how the complexity of care impacts the functioning of the team (CIHC, 2010) for patients with HF at EOL (Appendix C). To promote optimization of palliative team functioning, NPs should provide a holistic care perspective, build expertise in HF care for patients at EOL, and should resolve uncertainties about referring to palliative care.

Use a holistic perspective. Holistic palliative care requires collaboration (Psotka et al., 2017). Thus to facilitate collaborative care (CIHC, 2010) palliative care teams should share information. The palliative advanced home care and heart failure care (PREFER) model promotes holistic care for patients with HF at EOL and has been shown to provide relief from symptoms and social issues (Brännström & Boman, 2014). Although "specialty nurses, palliative care nurses, [a] cardiologist, [a] palliative care physician, [a] physiotherapist, and [an] occupational therapist" (Brännström & Boman, 2014, p. 1144) were the team members who provided the multidisciplinary care as part of the PREFER model, the NP role was not mentioned specifically in the literature. However, the findings from the PREFER model that suggests how collaboration can occur with palliative care teams to provide holistic care for patients with HF at EOL can be applied to NPs as they provide advanced specialty nursing.

In practice, use of the PREFER model may provide NPs with opportunities for collaboration to occur as the model foundation proposes that palliative care teams work closely together in providing patient-centered care for patients with HF at EOL (Brännström & Boman, 2012). For example, patients with HF and their family members could be provided with contact numbers to call a palliative team member if HF symptoms worsen (Brännström & Boman, 2012). Additionally, a palliative home care team could be made available to respond to patients with HF as needed and all palliative team members could meet biweekly to review the patient's medical treatment (Brännström & Boman, 2012).

Although the literature suggests the PREFER model could promote palliative team collaboration (Brännström & Boman, 2014), the model has not been implemented in standard practice for patients with HF at EOL. Nurse practitioners may experience several challenges in organizing and implementing the PREFER model in practice as the model includes after-hour care and palliative advanced home care teams (Brännström & Boman, 2012), services that NPs may not have available. Despite these challenges with implementing the model, NPs can continuously work with palliative teams to incorporate specific aspects of the model, such as the availability of after-hour care. Nurse practitioners can implement other components of the PREFER model in practice, such as providing specialized, team-based HF care at EOL that is patient-centered, structured, and easily accessible (Brännström & Boman, 2014). Also, NPs can include close family members and can support all members of the palliative team to provide holistic care (Brännström & Boman, 2014). Thus despite the inability to implement all aspects of the PREFER model as noted in the literature to optimize holistic care, NPs can still provide such care through collaboration with the palliative team.

Build expertise. Information sharing is a necessary part of collaboration "to avoid gaps, redundancies, [and] errors that impact both effectiveness and efficiency of care delivery" (CIHC, 2010, p. 14). Although the medical treatment of HF is well-established (Howlett et al., 2016), there remains a lack of evidence that describes specific palliative care measures during the EOL period in HF (Kaasalainen et al., 2011).

Symptom management for HF at EOL, adapted from the peer-reviewed Pallium Palliative Pocketbook, identifies specific recommendations that NPs can use in primary care (McKelvie et al., 2011). The symptom management recommendations by McKelvie et al. (2011) can be used to build expertise in the areas pertaining to non-pharmacological and pharmacological symptom management. Heart failure symptom management outlined by McKelvie et al. (2011) included the initial therapy for each symptom and the recommended pharmacological starting dose, which can be directly translated into NP practice for collaboration with palliative care teams. The BC Heart Failure Network (2017b) EOL clinical practice guidelines for HF symptom management should also be used by NPs and shared with the palliative team when providing care for patients with HF at EOL. Thus NPs can collaborate with palliative care teams by sharing the symptom recommendations by McKelvie et al. (2011) and the BC Heart Failure Network (2017b) to promote the delivery of patient-centered palliative care at EOL.

While sharing the HF symptom management recommendations by McKelvie et al. (2011) and the BC Heart Failure Network (2017b) facilitates collaboration between NPs and the palliative care team to provide EOL care for patients with HF, NPs need to decide the ideal time to share these recommendations. McKelvie et al. (2011) suggests symptom management recommendations for patients with HF at EOL although does not indicate when the ideal time to address these symptoms should be in practice. To develop an EOL care plan that supports patient-centered care, NPs should share the symptom management recommendations with the palliative team once the palliative referral has been made as “palliative care plays an important role in relieving suffering and distress in patients [with HF] and caregivers” (Klindtworth et al., 2015).

McKelvie et al. (2011) also suggest that practitioners incorporate the elements of the CCM. There is strong guideline recommendation for the use of the CCM to structure and deliver EOL palliative care for patients with HF (McKelvie et al., 2011). The CCM, adapted from Evidence on the Chronic Care Model in the New Millennium, can be implemented by NPs to collaborate with palliative care teams through community assessment surveys, stakeholder engagement, and healthcare funding and service proposals. Nurse practitioners can support building expertise regarding care for patients with HF at EOL by developing or improving elements of the CCM such as community resources and policies; healthcare organization; self-management systems; delivery-systems, decision-support, and clinical informatics (McKelvie et al., 2011). Elements of the CCM can be implemented by NPs through collaboration with the palliative team. For example, NPs can engage and meet with the palliative team to discuss ways to improve EOL community resources and can develop policies and connections that will support the development of palliative out-patient programs for patients with HF (McKelvie et al., 2011). A practical application of this can include the development of a patient and family support group for patients with HF at EOL. To build expertise, NPs can be present during support group sessions and can request a member of the palliative team, such as a palliative nurse consultant or a palliative care physician, also be in attendance. Support groups can also be offered via teleconference to overcome rural and remote accessibility issues.

To improve patient-centered EOL care, NPs can collaborate with palliative care teams by arranging meeting intervals to implement elements of the CCM as suggested by McKelvie et al. (2011). Nurse practitioners should consider that implementation of this model may be limited by a lengthy process that may require health authority approval and financial resource support. Even so, NPs can work collaboratively with palliative care teams through scheduled set meeting times by deciding the particular elements of the CCM that would be a priority for patients with HF.

Nurse practitioners can also identify pre-existing available EOL resources that can be used to support the development of elements of the CCM. For example, NPs can propose the development of a working group with the purpose of creating reminders and templates in electronic medical records (EMRs), often used in primary care regionally. By creating reminders and templates in EMRs focused on assessing symptom management recommendations for patients with HF at EOL, NPs can assess symptom burden during each patient encounter in primary care to guide treatment.

Resolve uncertainties about the referral process to palliative care. Uncertainties regarding the referral process to palliative care, particularly timing and patient acceptance, are barriers towards patients with HF receiving EOL care (Hauptman et al., 2008). There were no findings that suggest ways NPs can resolve referral uncertainties. Although as previously mentioned in this paper, the ideal timing for a referral to palliative care for patients with HF at EOL is preferred early in the HF disease trajectory (LeMond & Allen, 2011). Nurse practitioners can refer their patients to palliative care prior to the patient reaching Stage II HF and preferably prior to the patient being hospitalized as a result of worsening symptoms (Jaarsma et al., 2009).

In the findings cardiologists, geriatricians, internists, and family physicians were uncertain if their patients with HF would be accepted to palliative care (Hauptman et al., 2008), which may lead to a delay in referral. This delay can result in patients with HF not receiving patient-centered palliative EOL care. Nurse practitioners can mitigate uncertainties regarding referrals to palliative care for patients with HF by utilizing the EOL tools through the BC Heart Failure Network (2017b). Nurse practitioners can utilize the clinical practice guidelines for symptom management EOL tools created by the BC Heart Failure Network (2017b) to provide HF care that is patient-centered and focused on EOL.

Engage in Conflict Resolution

By asking patients if they have treatment concerns, NPs are collaboratively engaging with the patient by reassuring them that their treatment is not being abandoned, that their emotions are validated by the NP, and that it is important to clarify misunderstandings (Allen et al., 2012). Nurse practitioners can also utilize the six-step approach to goal setting during patient visits suggested by Ahia & Blais (2014) to resolve conflict by identifying current sources of conflict, reflecting on previous causes of conflict, and in showing empathy (Ahia & Blais, 2014). This approach, which emphasizes that conflict resolution is needed to collaborate with palliative care teams for patients with HF at EOL, can be implemented by NPs to assess for gaps in knowledge, differences in treatment goals amongst the team, grief, and family influences (Ahia & Blais, 2014).

While NPs can implement the conflict resolution recommendations described by Allen et al. (2012) and Ahia and Blais (2014) during each patient visit, this may not be easily achievable for NPs in practice. This is because conflict may be difficult to resolve as palliative care involves many complexities (Klarare, Hagelin, Fűrst, & Fossum 2013). For example, NPs are not able to control for issues outside of practice that affect collaboration amongst the palliative care team "such as social issues with substance abuse, interfamily relations, or legal implications of impeding death" (Klarare et al., 2013, p. 1066). Nurse practitioners can assist with alleviating social-related issues for patients with HF and can provide patient-centered multidisciplinary support in these instances by referring to social work to resolve sources of conflict.

Limitations

The main challenge that was revealed during this project is the lack of literature to suggest how NPs specifically can collaborate with palliative care for patients with HF at EOL. The ways NPs can collaborate with palliative care teams for patients with HF at EOL were inferred from the findings, which suggest how physicians can collaborate. Even then, the literature was largely vague and unclear as there were few suggestions for practice that described particular details to assist in answering the *how* part of the research question such as when collaboration should occur, specifically with whom, where, and on what grounds. The research suggested ways that NPs can collaborate, mainly with the sharing of documents and tools and the implementation of models for practice, although a more thorough approach to collaboration for patients with HF at EOL needs to be described in future research. Another issue is that despite NPs collaborating with palliative care teams to provide patients who have HF with EOL care, the issue remains that many patients do not receive palliative care as a result of eligibility criteria that limits access to this service.

The types of evidence retrieved in the literature search was found to be mainly level C utilizing a qualitative design, followed by level E. Only two articles and one guideline were published in Canada as most of the evidence was completed in the U. S. and the U. K. Therefore some may view that the evidence lacks a Canadian perspective. Even though there was limited Canadian evidence that can inform the research question, the guideline by McKelvie et al. (2011) published in Canada was a pivotal article in the project. This is because McKelvie et al. (2011) provided the most relevant evidence, which could be used to inform how collaboration can occur to provide care to patients with HF at EOL. Additionally, as the majority of evidence found in the literature search was level C, the results of the qualitative studies are unique to the sample studied and difficult to replicate. Nevertheless, the qualitative research designs provided rich and valuable subjective experiences of patients with HF at EOL and care providers that collectively attributed towards informing the research question. The evidence is clear that collaboration is a highly valued aspect of palliative care for patients with HF at EOL.

Implications for Practice

If NPs are unaware of the resources available to guide EOL care for patients with HF, then without collaboration, these patients may not receive the holistic care they need during this pivotal time. Nurse practitioners should be concerned that their patients with HF are not receiving holistic care at EOL, as palliative care services can be inaccessible for many patients with HF due to palliative eligibility criteria. Therefore, there are practice implications and recommendations that NPs should consider. These practice implications include addressing barriers to palliative care services for patients with HF at EOL and providing EOL care despite a declined palliative referral.

The literature findings do not all reflect the reality of accessing palliative care in BC. A barrier that NPs will experience trying to refer patients with HF at EOL to palliative care includes a referral requirement that stipulates a physician written request, as is the case in NH (2015). There may be confusion for NPs in trying to organize a referral to palliative care while the current NH palliative strategy indicates a written physician request is required for service (NH, 2015). Although NPs can collaborate with a physician to complete a written referral, NPs should be authorized to request a referral to palliative care themselves as autonomous care providers (CRNBC, 2017b). Therefore to provide continuity of care, NPs should be encouraged to collaborate with palliative care teams, such as with the palliative team in NH, to request that the next revision of the NH palliative strategy referral requirements be changed to include NP requests for referral to reflect current practice.

Optimizing communication, promoting leadership, clarifying roles, promoting team functioning, and resolving conflict are ways suggested in the findings that NPs should use to collaborate with palliative care teams to promote a multidisciplinary approach. However, a palliative referral may be declined by a palliative care program. Therefore, another implication for NP practice is that despite a declined palliative referral, as the patient’s primary care provider, NPs should take leadership and provide patients with HF at EOL a palliative approach where appropriate. By providing a palliative approach, NPs may facilitate holistic care that is tailored to reflect the patient’s preferences, wishes, and values for EOL.

Additionally, NPs should remember that patients with HF are an important member of the palliative team. Hence the recommendations in the findings that suggest how NPs can address the barriers to EOL care for patients with HF can also be used to collaborate with palliative teams. For that reason, NPs do not need to wait for an approved referral to palliative care services before EOL palliative care can be implemented by NPs.

Future Research

Future research is needed to explore how NPs can collaborate with palliative care teams as the research findings were inferred, the research field on the topic was found to be relatively new, and there were few Canadian studies that informed the research question. The evidence was inferred from studies that focused on how physicians can collaborate as there were no articles that informed the research question directly. As primary care providers, the findings can be applied to NPs although evidence focusing exclusively on how NPs can collaborate with palliative care teams for patients with HF would be beneficial towards expanding the field of NP research. Also, the majority of the research was recent as the oldest article retrieved in the search was from 2002 and the majority of articles were published between 2008 and 2017. While the majority of the evidence informing collaboration in HF care for EOL was found published within the past ten years it is likely that as the number of NPs emerging onto the field grows, research describing collaborative practice for patients with HF is also likely to expand and inform practice. As the findings are applicable to Canada, future research should focus on collaborative practices for patients with HF at EOL within a Canadian context to account for the differences in healthcare practices between countries.

Conclusion

There have been important revelations that have been made during the course of this NP integrative review. Even though current guidelines provide recommendations for HF care at EOL, there is little evidence specific to NP practice. There are resources and tools for the care of patients with HF at EOL that can guide NPs towards collaborative care with palliative teams, but these are often underutilized due to challenges with predicting the disease trajectory in HF and recognizing EOL. Nurse practitioners should work towards closing the current gap between knowledge and practice in providing collaborative EOL care for patients with HF so patients can receive the benefit of holistic, multidisciplinary care that reflects their preferences prior to death.

To provide patients with HF with quality EOL care, NPs can collaborate with palliative care teams by optimizing communication, taking leadership, clarifying palliative team roles, promoting team functioning, and resolving conflict (CIHC, 2010) (Appendix C). The CIHC framework was useful in conceptualizing collaboration and informing how interprofessional collaboration is achieved in healthcare (2010). Therefore it is important for NPs to recognize that collaboration is a continuous process and has multiple considerations.

In summary, in using the CIHC framework (2010), there are several ways that NPs can collaborate with palliative care teams to provide patients who have HF with EOL care (Appendix C). Although, NPs need to consider that there is no simple answer. Despite the current evidence, there are knowledge gaps in the literature that should be addressed by NPs to inform future practice. With the growing trend in NP practice, it is likely that literature to inform NP practice for patients with HF, particularly at EOL will arrive in the near future.

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Table 1

Headings, Medical Subject Heading Terms, and Search Terms

Criteria	**CINAHL Headings**	**MeSH Terms**	**PsychInfo**
Nurse Practitioner	Nurse Practitioners Family Nurse Practitioner Physicians, Family	Nurse Practitioners Family Nurse Practitioners Physicians, Family Physicians, Primary Care	Nurse Practitioners Family Nurse Practitioners Family Physicians
Primary Care	Primary Health Care	Primary Health Care	Primary Health Care
Collaborative	Collaboration	Collaboration Cooperative Behavior	Collaboration
Palliative Care Teams	Terminal Care Hospice Care Palliative Care	Terminal Care Hospice Care Palliative Care	Hospice Palliative Care
End of Life	Terminally Ill Patients Hospice Patients Advance Directives	Terminally Ill Patients Hospice Patients Advance Directives	Terminally Ill End of life
Heart Failure	Heart Failure Dyspnea, Paroxysmal Ventricular Dysfunction Ventricular Remodelling Heart Hypertrophy	Heart Failure Cardio-Renal Syndrome Dyspnea, Paroxysmal Edema, Cardiac Heart Failure, Diastolic Heart Failure, Systolic Ventricular Dysfunction, Left Ventricular Dysfunction, Right Cardiomegaly Cardiomyopathy, Dilated Hypertrophy, Left and Right Ventricle	Heart Failure

Table 2

Comprehensive Search Strategy Used to Gather Evidence (December 1, 2016)

Search Terms	**Database**	**Total Number of Citations**
((“Family Nurse Practitioners”) OR (“Physicians, Family”) OR (“Nurse Practitioners”)) AND ((“Palliative Care”) OR (“Terminal Care”) OR (“Hospice Care”)) AND ((“Hypertrophy, Right Ventricular”) OR (“Hypertrophy, Left Ventricular”) OR (“Ventricular Remodeling”) OR (“Heart Failure”) OR (“Heart Hypertrophy”) OR (“Ventricular Dysfunction, Right”) OR (“Ventricular Dysfunction, Left”) OR (“Ventricular Dysfunction”) AND (“Primary Health Care”))	CINAHL	10
(“Nurse Practitioners”[Mesh] OR “Family Nurse Practitioners”[Mesh] OR “Physicians, Family”[Mesh]) AND (“Terminal Care”[Mesh] OR “Hospice Care”[Mesh]) OR “Palliative Care”[Mesh] AND (“Heart Failure”[Mesh] OR “Cardio-Renal Syndrome”[Mesh] OR “Dyspnea, Paroxysmal”[Mesh] OR “Edema, Cardiac”[Mesh] OR “Heart Failure, Diastolic”[Mesh] OR “Heart Failure, Systolic”[Mesh] OR “Ventricular Dysfunction, Left”[Mesh] OR “Ventricular Dysfunction, Right”[Mesh] OR “Cardiomegaly”[Mesh] OR “Cardiomyopathy, Dilated”[Mesh] OR “Hypertrophy”[Mesh]) AND “Primary Health Care”[Mesh]) (nurse practitioners OR family nurse practitioners OR family physicians) AND (terminal care OR hospice care OR palliative care OR end of life) AND (heart failure OR cardio-renal syndrome OR dyspnea, paroxysmal OR edema, cardiac OR heart failure, diastolic OR heart failure, systolic OR ventricular dysfunction, left OR ventricular dysfunction, right OR cardiomegaly OR cardiomyopathy, dilated OR hypertrophy) (nurse practitioners OR family nurse practitioners OR family physicians) AND (terminal care OR hospice care OR palliative care) AND (heart failure OR cardio-renal syndrome OR dyspnea, paroxysmal OR edema, cardiac OR heart failure, diastolic OR heart failure, systolic OR ventricular dysfunction, left OR ventricular dysfunction, right OR cardiomegaly OR cardiomyopathy, dilated OR hypertrophy)	PubMed	112

(Nurse practitioners OR Family nurse practitioners OR Family physicians OR primary care physicians) AND (palliative care OR hospice OR terminally ill OR end of life) AND (heart failure OR dyspnea OR ventricular dysfunction OR ventricular remodelling OR heart hypertrophy)	PsychInfo	14
(Heart Failure)	Social Work Abstracts	26
“nurse practitioners OR family nurse practitioners OR family physicians OR primary care physicians AND palliative care OR end of life OR hospice care OR terminally ill AND heart failure”	National Guideline Clearinghouse	45
TOTAL RETRIEVED		205

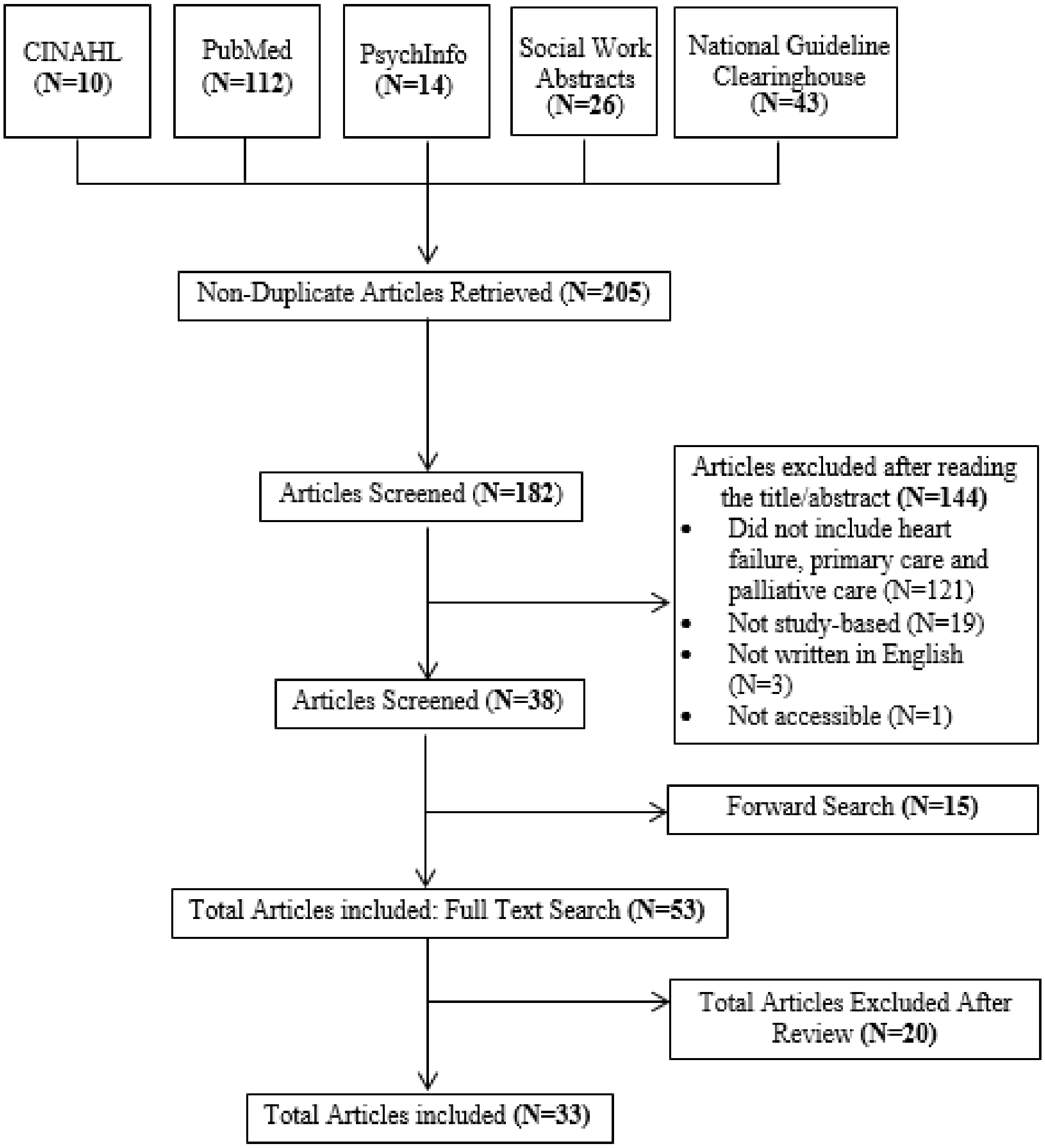

Figure 3. Literature Search Flow Diagram for Search Conducted December, 2016

Appendix A

Evidence Matrix of Literature Retrieved (N=33)

Author, (Date), and Article Location	**Study Design and (Level of Evidence)**	**Sample**	**Study Purpose**	**As Related to NP Project**			
				Study Purpose	**Key Findings**	**Strengths**	**Limitations**
Afshar et al. (2016), Germany	Literature Review (E).	Search of the databases PubMed and Scopus using PRISMA criteria. Articles published within the past 5 years were chosen (N=127).	• Describe current discussion points in generalist palliative care for non-cancer patients at end of life.	• Answer: How does collaboration occur for patients with heart failure at end of life?	"Needs-based care planning in the end-of-life phase is facilitated by actively discussing care issues in the physician-patient consultation as early as possible and including family members in the decision-making process" (p. 3). • Supportive and Palliative Care Indicators Tool (SPICT) to identify patients with chronic illnesses that could benefit from palliative care.	• General practitioners are a key feature in end of life care. • Non-cancer patients dominate in generalist palliative care. • Content and structure is essential in the provision of palliative care. • Palliative care needs should be identified. • Tool development for practice and palliative assessment in general practice to be initiated. • Emphasis on the "increasing need for intervention studies …now that papers have so far mainly focused on the description and analysis of the current situation" (p. 5).	• Minimal discussion regarding unique challenges faced by patients with heart failure at end of life in need of a palliative approach.

Ahia & Blais (2014), United States	Case Report (E).	Case report (N=1) of a 71 year old male with chronic obstructive pulmonary disease, heart failure, and dementia.	• Describe effective communication that occurs at end of life and how to implement it into practice.	• Answer: How does continuity of care occur for patients with heart failure at end of life requiring palliative care?	"For setting goals of care, align the patient's values and preferences with the medical team's goals" (p. 706). "The use of a functional status scale such as the Palliative Performance Scale can help to further refine prognostication within the year" (p. 706).	• Primary care physicians are important in providing palliative care and in determining patient goals of care.	• The author's perceived beliefs may have impacted the findings.
Allen et al. (2012), United States	Scientific Statement, Expert Consensus (E).	Expert peer review panel according to the Office of Science Operations for the American Heart Association.	• Assist care providers in communication techniques that facilitate decision making in heart failure.	• Describe ways to collaborate with palliative care teams.	• An annual review visit in primary care with heart failure patients to discuss symptom burden, goals of care, prognosis, patient preferences and advance care planning. • Palliative care to be discussed when heart failure advances; ensure adequate treatment management and evaluate whether the management matches the patient's goals.	"Palliative care teams can consist of physicians, nurses, social workers, chaplains, and other professionals who work to ensure that patient and caregiver needs are assessed and met" (p. 1937).	• Despite indicating that it needs to be done, there is little suggestion given regarding how to provide patients with heart failure with end of life care.

					• Shared decision making is essential to palliative care heart failure management.		
Bekelman et al. (2011), United States	Descriptive, Interviews (C).	Purposive sampling. Eligible patients were in New York Heart Association Class II-IV (n=33) adult outpatients and (n=20) family members.	• Examine patients with heart failure and caregiver experiences and to better understand the impact of palliative care.	• Answer: how do patients with heart failure at end of life and their caregivers experience palliative care?	• Patients with heart failure and caregivers would prefer early supportive care aimed towards adjusting to their illness, symptom management and a team approach. • Palliative care preferred early and coordinated by a provider knowledgeable about their condition and was familiar with them.	• Identifies the use of a collaborative care model to address patient concerns regarding care collaboration.	• Minimal suggestion given regarding how to implement a collaborative care model to better coordinate palliative care for patients with heart failure at end of life.
Boyd et al. (2009), United Kingdom	Descriptive, Interviews and Focus Groups (C).	Purposive sampling method. Patients (New York Heart Association Class III-IV), family members, and health professionals (N=162).	• Describe the key features of services for people with advanced heart failure and evaluate recommendations for care.	• Explore how to provide effective patient-centered care for advanced heart failure including potential barriers.	• Patients and families preferred one key health professional to coordinate care for patients with heart failure at end of life. • Difficulties with prognostication delayed advance care planning.	• Multidisciplinary care and communication is important for heart failure patients at end of life.	• Minimal suggestion given regarding how to improve support multidisciplinary care and communication for heart failure patients at end of life.
Brännström & Boman	Prospective, Randomized	The palliative advanced	• Evaluate the palliative advanced	• Answer: How should palliative	• Stepwise approach to	• Study was the first to “evaluate a new	• Despite indicating the important team approach

(2014), Sweden	(B).	home care and heart failure care intervention group (n=36) or the usual care (n=36). Patients were confirmed to have heart failure with New York Heart Association Class III-IV.	home care and heart failure care intervention for patients with heart failure in regards to symptom burden, and functional class.	care be provided for patients with heart failure at end of life?	palliative care: 1) confirm diagnosis, 2) patient education, 3) establish an advanced care plan, 4) organize services, 5) symptom management, 6) identify end-stage heart failure, 7) breaking bad news, 8) establish new goals of care.	approach for congestive heart failure management by integrating specialist palliative home care and heart failure care” (p. 1149).	in HF palliative care, there is minimal suggestion given regarding how to implement palliative care for patients with heart failure at end of life.
Chandar et al. (2016), United States	Descriptive, Survey (C).	Cardiologists, oncologists, primary care providers, and cardiology and oncology support staff (N=117).	• Explore attitudes of oncologists, cardiologists, and primary care physicians in regards to advance care planning for patients with advanced cancer and advanced heart failure.	• Describe the barriers to advance care planning for patients with heart failure at end of life.	• 15% of cardiologists felt they should initiate advance care planning discussions with patients with heart failure. 2) 68% of oncologists felt they should initiate advance care planning discussions with patients with advanced cancer. • 68% of primary care physicians felt they should initiate advance care planning	“A partnership with primary care providers may also ease the discussion of ACP; our findings suggest that oncologists were more accepting of collaborating with a primary care provider than cardiologists” (p. 5).	• Minimal discussion regarding how to overcome barriers to advance care planning for patients with heart failure at end of life.

					with patients with heart failure; 34% for patients with terminal cancer.		
Daley et al. (2006), United Kingdom	Descriptive, Interviews (C).	Referrals to the Heart Failure Specialist Nurse service between 2002 and 2005 (n=491). Community palliative care team referrals (N=1500). Ten patients ≥ 80 years were sampled in regards to emerging themes.	• Explore collaboration between the Heart Failure Specialist Nurse service and palliative care services in the United Kingdom.	• Explore patient experiences in regards to receiving the Heart Failure Specialist Nurse service in collaboration with palliative care services.	• Qualitative benefits from attending the support group include helping patients cope with physical, psychological, and social isolation, and a loss of self-esteem and worth. • The support group generated hope and purpose for participants.	• Heart Failure Specialist Nurses are effective team members in providing care throughout the illness trajectory. • Support groups in heart failure are effective.	• The study findings are specific to the available services and funding in the location of the United Kingdom and may not be generalized to other countries.
Davidson et al. (2004), Australia	Literature review, expert consultation, local needs assessment (C, E).	Consecutive deaths between 1999-2000 in the St. George Heart Failure service, home-based arm (N=121).	• Explore if a comprehensive palliative care approach model within a heart failure management program.	• Explore the effect of a comprehensive palliative care approach model within a heart failure management program.	• Focus group members revealed an overall sense of discomfort in managing palliative patients coupled with a knowledge deficit in terms of understanding palliative philosophies and resources.	• Combined study designs contributed a broader understanding regarding the lack of understanding of palliative care for patients with heart failure at end of life.	• Emphasis on the need for knowledge development of palliative care principles in relation to caring for patients with heart failure at end of life although does not indicate the type of knowledge.
Dev et al. (2012), United States	Systematic Review (C).	(N=19) articles.	• Explore the need for improved quality and patient-centered palliative care for patients with heart	• Answer: How do patients with heart failure experience palliative care at	• Physicians are often unaware of advance directives and uncommonly	• Support “to suggest that, to achieve widespread advance directive completion, care providers will	• Offered strategies for improving end of life care for patients with heart failure although no specific detail given.

			failure at end of life.	end of life.	discussed this with their patients.	need to engage in proactive counselling and education of patients” (p. 314). • Despite this support, “however, there is not a consensus recommendation on how to coordinate advance care planning between HF providers, palliative care specialists, and the patient’s other providers” (p. 314). “The meta-message is that intervention must be matched to patient goals of care and needs-personalization is critical” (p. 317). • Recommendation that the new subspecialty certification in advanced heart failure should include a formal palliative care curriculum.	
De Vleminck et al. (2014), Belgium	Descriptive, exploratory using focus groups and purposive sampling (C).	Five focus groups in March 2012 (N=36).	• Identify barriers to advance care planning from general practitioner perspectives and gain knowledge regarding the differences between different illness trajectories.	• Answer: How can barriers to advance care planning be overcome to provide palliative care for patients with heart failure at end of life?	• Barriers to advance care planning include lack of communication, challenges with predicting the heart failure illness trajectory,	• Study “is the first qualitative study providing in-depth insight into the similarities and differences in the barriers to initiation of ACP between cancer, heart failure,	• Perspectives limited to general practitioners only.

					and attitudes and beliefs regarding advance care planning.	and dementia patients, as perceived by the GP" (p. 7)	
Diop et al. (2017), United States	Systematic Review and Meta-Analysis (A).	(N=15) studies were isolated. (n=10) were prospective. (n=5) retrospective.	• Identify and evaluate interventions for heart failure palliative care patients.	• Answer: How can team-based palliative care interventions be implemented?	"The studies with improvement in the largest number of outcomes prioritized the integration of interdisciplinary HF and palliative care" (p. 89).	"Through categorizing study design, palliative interventions, and outcomes, this summary provides direction for future projects" (p. 90).	• Minimal discussion regarding how to overcome barriers to advance care planning for patients with heart failure at end of life.
Dunlay et al. (2014), United States	Descriptive, Surveys (C).	Physicians, nurse practitioners, physician assistants (N=95).	• Investigate clinician practice, expectations, and comfortability in discussing care goals and in providing patients with heart failure with end of life care.	• Answer: How are patients with heart failure given end of life care?	"In total, seven NP/PA (16%) and two physicians (4%) reported never discussing prognosis" (p. 262). "…, respondents varied in who they felt should have responsibility for providing EOL care" (p. 263). Rates of referral to palliative care were higher for tertiary care.	• The study identified that the most common reasons for palliative referral included when there were no other care options, to augment planning for future care, hospice referral, and symptom management.	• The lowest responses were from primary care clinicians thus may lack generalizability to nurse practitioners.
Evangelista et al. (2014a), United States	Descriptive, Questionnaire (C).	Patient participants were recruited from an inpatient setting through heart	• Explore outpatient palliative care services that are consumed by New York Heart Association II-III patients after	• Describe how and when palliative care referrals occur for patients with advanced heart failure.	• All the patients who pursued additional palliative care services were referred to a pharmacist that	• Provided support to show that ongoing versus episodic palliative care resulted in improved symptom control.	• No explanation for how palliative care referrals occur.

		failure referrals (New York Heart Association II-III) (n=36).	discharge from hospital as a result of exacerbation.		worked with the palliative care specialist. 20 patients pursued social work support. 19 and 16 patients were referred to occupational therapy and psychiatry respectively. 13 patients met with the chaplain.		
Evangelista et al. (2014b), United States	Descriptive, correlational and prospective, single cohort (C).	Participants were given a study packet, and then a telephone interview was arranged prior to the palliative consultation. A follow-up telephone call was arranged three months later.	• Explore if patients with advanced heart failure who receive more than two palliative care consultations three months after an acute exacerbation have more perceived control, involvement, and an improved symptom burden.	• How do patients with heart failure at end of life receive palliative care services?	• Patients receiving ongoing palliative care reported better perceived control, involvement and symptom management.	• Provides support to initiate palliative care early in the heart failure disease trajectory.	• No link given between perceived control and how patients with heart failure received end of life care.
Fendler et al. (2015), United States	Literature Review (E).	(N=10) articles.	• Describe the most effective way to implement palliative care for patients with heart failure at end of life.	• Describe the most effective way to implement palliative care for patients with heart failure at end of life.	• Palliative care should be initiated early in the heart failure disease trajectory. • Collaboration should occur in heart failure. • A leader should	• Identification of what team-based heart failure palliative care should entail including how providers should implement it.	Unclear methodology.

					be designated to coordinate the multidisciplinary heart failure care. • No agreed upon timing of location to implement palliative care. • Many healthcare providers make-up the team, including patients and families although the three main specialties include primary care, cardiology, and palliative care.		
Gadoud et al. (2014), Unites States	Descriptive, Observational (C).	Use of the Clinical Practice Research Datalink database of anonymous electronic medical records from primary care to determine patients registered as needing a palliative approach (N=27 689). The Clinical Practice	• Answer: is there an imbalance in the palliative care approach provided to patients with heart failure at end of life?	• Answer: When are patients with heart failure at end of life provided with a palliative approach?	• In the heart failure arm, one third of heart failure patients were only entered into the palliative care registry one week prior to dying.	• Large, population-based sample.	• Estimation was designated regarding sudden death; if the number of sudden deaths were over-estimated then only 10% of patients with heart failure were recognized as requiring palliative care.

		Research Datalink database represents 8% of the population of the United Kingdom.					
Goodlin et al. (2004), United States	Consensus conference and literature review (E).	Consensus conference comprised of experts in advanced heart failure, palliative medicine, geriatrics, outcomes measurement, and health care improvement.	• Identify the gaps in the literature regarding palliative care for patients with heart failure at end of life.	• Answer how to identify when a patient with heart failure is nearing end of life	• Multidiscipline care is required for palliative patients with heart failure to improve their quality of life. Due to challenges with prognostication, end of life planning should be done early in the heart failure disease process.	• Emphasizes the need for coordinated and planned care of heart failure patients at end of life.	• No clear indications for how interdisciplinary care should be implemented for patients with heart failure at end of life.
Gott et al. (2007), United Kingdom	Prospective, Longitudinal (C).	Decedents of a longitudinal study >60 years from GP surgeries (N=27).	• Describe the dying trajectories in heart failure.	• Describe the dying trajectories in heart failure.	• Several types of dying trajectories found.	• Identification of the risk of inappropriate resource allocation that meets only a small number of patient needs.	• A common heart failure trajectory was not identified in the study.
Hanratty et al. (2002), United Kingdom	Descriptive, Focus groups (C).	General practitioners and consultants in cardiology, geriatrics, palliative care, and general medicine (N=34).	• Explore physician perspectives regarding the need for palliative care in heart failure including barriers.	• Explore physician perspectives regarding the need for palliative care in heart failure, including barriers.	• The general practitioner should be the key team player in organizing palliative care services. • Barriers to achieving palliative heart failure care	• Provided practical insight regarding physician perspectives in caring for patients with heart failure at end of life.	• The study does not provide a multidisciplinary perspective to palliative care as the focus lies on physicians.

					include health care organization, the unpredictable disease trajectory, and role understanding. - Priorities should include enhancing the role of the nurse, better primary care support, and improved communication between all health professionals.		
Hauptman et al. (2008), United States	Pilot study, Survey (C).	1) Pilot study of family physicians, geriatricians, and cardiologists (N=68) 2) Random sample cardiologists, internal medicine, geriatricians, family practice (N=1450).	- Explore physician perspectives regarding risk stratification, device management, and care options in advanced heart failure.	- Explore how challenges with heart failure prognostication impacts palliative care referral timing, device deactivation, and patient experience.	- 15.7% of physicians indicated they felt confident that they could consistently predict death. - Majority of respondents indicated they could predict death rarely or on occasion. - Discussion with patients regarding implantable cardioverter defibrillator implantation was typically uncommon. - Physicians reported they should be the	- In the care of the physician with a history of palliative care training and being in a group practice were found to be physician characteristics that led to higher confidence levels.	- Unclear from the study how physician perspectives impact care options for patients with heart failure at end of life.

					ones to inform patients about death and dying versus other healthcare providers.		
Hopp et al. (2010), United States	Systematic Review (C).	Use of the Cumulative Index to Nursing and Allied Health, Medline, and PsychInfo databases (N=1046). After inclusion/ exlusion criteria (n=15).	• Identify how patients with heart failure experience their condition.	• Explore how patients with heart failure perceive care at end of life.	• Patients experience systems-related challenges, life disruptions, social isolation, symptom-burden, and uncertainties about life. • Patients with heart failure cope through management of the condition, working through the process of dying, and with social support.	• Identification that patients with heart failure may experience poor health care coordination compared with other illnesses. • The social worker can be an advocate, can provide compassion, and can coordinate care.	• Minimal suggestion given regarding how to improve the poor health care coordination that occurs for patients with heart failure.
Ivany & While (2013), United Kingdom	Literature Review (E).	Published articles between 2000 and 2013. Articles that met the inclusion criteria (N=10).	• Identify patients with heart failure palliative care needs and how nurses can deliver quality palliative care, particularly in the home environment.	• Describe how patients with heart failure receive palliative care.	• Communication is the key to patient-centered care yet is lacking for patients with heart failure needing palliative care. • Prognostication challenges make it difficult to initiate conversations about palliative care.	• Provides support for the notion that patients with heart failure at end of life have specific palliative care needs "that could be effectively met by specialist community palliative care services" (p. 444).	• Despite mentioning the barriers to receiving palliative care, there is little suggestion given regarding how to improve palliative care for patients with heart failure at end of life.

					• There are continued care gaps in community services despite the Gold Standards Framework.		
Kaasalainen et al. (2011), Canada	Descriptive, Interviews (C).	Purposive and theoretical sampling (n=8) patients in New York Heart Association Class IV (n=10) informal caregivers (n=11) nurse (n=3) physicians (n=3) pharmacists.	• Describe the care process that palliative adults with heart failure, families, and care providers experience in the community.	• Describe how palliative care is coordinated for patients with heart failure at end of life in Canada.	• Challenges with heart failure prognostication impacted palliative care services. • Delayed palliative care referrals often resulted in little time spent with the patient and family. • Family members may have hindered the transition to palliative care. • All participants felt continuity of care was lacking. • Health professionals felt the need to build expertise in heart failure. • A lack of communication hindered collaboration.	"The findings from this study highlight the vulnerability of those adults who are dying from advanced heart failure and their family caregivers, and the misalignment of current end-of-life services in a Canadian community" (p. 50). "…challenges to achieving these desired outcomes of care were related to coordination of services within the health care system" (p. 51).	• Minimal suggestion given regarding how to implement a more collaborative approach for patients with heart failure at end of life.
Kavalieratos et al. (2014),	Descriptive, Interviews (C).	Stratified purposive	• Identify the perceived barriers to	• Answer: How do patients with	• Strategies to improve palliative	"This is the first [United States] study	• Despite indicating the barriers to palliative care,

United States		sampling to enlist primary care, cardiology, palliative care physicians, and non-physician care providers. Chain referral allowed. (N=18).	palliative care that affect patients with heart failure.	heart failure at end of life receive palliative care services?	care referral to focus on providing additional training during graduate or postgraduate training.	to explore barriers to palliative care referral for advanced HF among providers frequently caring for these patients" (p. 8).	there is little suggestion given regarding how to overcome these barriers for patients with heart failure at end of life.
LaDonna et al. (2016), Canada	Descriptive, Interviews (C).	Patients with advanced heart failure (New York Heart Association Class III-IV) recruited from heart failure clinics (N=62).	• Describe how patients with heart failure perceive their care team and team member roles.	• Identify the potential palliative team members.	• 2-19 team members were identified. Caregivers, nurses, family physicians, and cardiologists were often identified as members of the team. • Additional team members perceived included dentists, foot care specialists, drivers, housekeepers, and spiritual advisors.	• The study identifies that there are many team members involved in the care of patients with advanced heart failure versus the Canadian Cardiovascular Society 2008 Guideline that describes the team of mainly specialist collaborations with primary care physicians.	• Some description of each role given although vague.
LeMond & Allen (2011), United States	Literature Review (E).	Not specified.	• Describe how palliative care interventions can be implemented into the care of patients with heart failure.	• Answer: How is palliative care integrated for patients with heart failure at end of life?	• Risk scores can be used to calculate life expectancy. • Health care providers treating advanced heart failure should	• Objective information regarding prognostication has not shown to improve communication or end of life care decisions in the intensive care setting.	• Despite indicating that it needs to be done, there is little suggestion given regarding how to implement palliative care for patients with heart failure at end of life.

					regularly reassess life expectancy to know when to plan for and discuss palliative measures.	• Improvements in prognostic accuracy not enough to improve the care for patients with heart failure at end of life; providers must have the background knowledge to follow-through. • Advance care planning needs to occur or patients with heart failure are likely to die in an inpatient setting.	
Lewis & Stephens (2005), United Kingdom	Literature Review (E).	Search of the Cumulative Index to Nursing and Allied Health, Medline, National Electronic Library for Health, and the British Society of Heart Failure between 1990-2004.	• Evaluate the differences in a palliative care treatment approach for patients with heart failure versus those with other life-limiting illnesses.	• Explore how to improve palliative care for patients with heart failure at end of life.	• Heart failure patients need a palliative care approach. • The main barrier to palliative care in heart failure is care provider lack of understanding. • Communication is lacking in heart failure care management.	• Identification that frameworks are needed to optimize the care of patients with heart failure at end of life and to prevent fragmentation of care.	• Minimal detail given regarding how to implement frameworks to suggest care for patients with heart failure at end of life.
McKelvie et al. (2011), Canada	Guideline (C)	Canadian expert consensus panel.	• Provide recommendations for heart failure care in the setting of renal failure, sleep apnea, palliative care, and mechanical circulatory support.	• Describe the recommendations for palliative patients with heart failure at end of life.	• Palliative care should be based upon an assessment of needs and symptoms versus life expectancy. • Use of an interdisciplinary	• Evidence in support of the chronic care model.	• No recommendation given regarding how to initiate palliative care referrals.

					chronic care model for advanced heart failure.		
Michigan Quality Improvement Consortium (2012), United States	Guideline, Expert consensus (C).	PubMed, Google, the Respecting Choices website, and the Physician's Orders for Life Sustaining treatment websites.	• Provide advance care planning direction for providers.	• Describe how advance care planning can be used to collaborate with palliative care teams.	• Early patient goal identification and choices for care. • Early advance care planning discussions. Advance care planning should include family members, the surrogate decision-maker, and others close to the patient. Any individual can start the advance care planning discussion. • The advance care planning facilitator should have knowledge regarding the patient's condition in the progressive stages of the disease.	• Identification of specific recommendations for practice.	• Minimal suggestion given specifically in regards to advanced heart failure.
Seamark et al. (2002), United Kingdom	Cohort, Retrospective (C).	Two general practices; one urban, one rural (N=548).	• Explore if it possible to easily identify: symptomatic heart failure in general practice; if the mortality rate of	• Explore if primary care patients with advanced heart failure receive palliative care	• Palliative care was initiated in less than half of cases for those patients not dying suddenly or from	• Primary care providers are generally aware that a palliative approach is needed in advanced heart	• There may be an underestimate of palliation in the study and this may have skewed the results.

			patients with heart failure mirror those in published literature, and if patients with advanced heart failure receive palliative care towards death.	towards death.	cancer.	failure.	
Wotton et al. (2005), Australia	Descriptive (C).	Purposive sampling of senior registered nurses (N=17).	• Describe registered nurse perceptions of factors that impact the care of palliative end stage patients with heart failure.	• Explore if palliative care teams can work with cardiac teams to optimize the care of patients with heart failure at end of life.	• Knowledge of the patient and health system inadequacies impact patients with heart failure at end of life.	• Recommendations for practice based on the study findings.	• Perceptions of patients with heart failure receiving palliative care at end of life are limited to one profession.
Yancy et al. (2013), United States	Guideline (C).	Expert consensus used to formulate suggestions.	• Specify guidance for the adult diagnosis and management of heart failure.	• Identify the recommendations for palliative heart failure care.	"Palliative and supportive care is effective for patients with symptomatic advanced HF to improve quality of life" (p. 1835).	• Evidence in support of palliative care for patients with heart failure at end of life.	• No recommendations given regarding how to implement palliative care.

Appendix B

Concept matrix of factors to address in achieving collaboration.

Author and (Date)	**Barriers and Issues for Patients with Heart Failure Receiving End of Life Care**	**Leadership**
Afshar et al. (2016)		"”…it appears to be beneficial to use tools for the systematic and reliable identification of patients for palliative care and their needs and wishes so that appropriate palliative care can be commenced in a timely and appropriate manner" (p. 3) "One example is the Supportive and Palliative Care Indicators Tool (SPICT)" (p. 3) "Needs-based care planning in the end-of-life phase is facilitated by actively discussing care issues in the physician-patient consultation as early as possible and including family members in the decision-making process" (p. 3)
Allen et al. (2012)		"Patient and family education about options for formulating and implementing advance directives and the role of palliative and hospice care services with re-evaluation for changing clinical status is recommended for patients with HF at end of life" (p. 1847).
Bekelman et al. (2011)		"Patients and caregivers clearly expressed the need for help adjusting to the illness at or shortly after the diagnosis and then over time when needed" (p. 1321).
Boyd et al. (2009)	Ability to predict the HF disease trajectory.	
Chandar et al. (2016)		"Only 15.0% of cardiologists felt that it was their responsibility to conduct ACP conversations and write code status orders (CSOs) in their outpatient offices, and 57.7% reported never or rarely participating in ACP discussions" (p. 3)
Hanratty et al. (2002)	Ability to predict the HF disease trajectory.	
Goodlin et al. (2004)	Ability to predict the HF disease trajectory.	
Lewis & Stephens (2005)	Ability to predict the HF disease trajectory.	
Dev et al. (2012)		"In SUPPORT, patient awareness and completion of advance directives were limited; Teno et al. reported that 62% of 1905 seriously ill hospitalized patients were knowledgeable about living wills but only 42% were aware of durable power of attorney for health care" (p. 314). "To achieve widespread advance directive completion, care providers will need to engage in proactive counselling and education of patients, … however, there is not a consensus recommendation" (p. 314).

De Vleminck et al. (2014)	Ability to predict the HF disease trajectory.	“Although the GPs identified end-of-life care conversations as an important aspect of general practice, many of them were not familiar with the term ACP” (p. e84905)
Dunlay et al. (2015)	Ability to predict the HF disease trajectory.	“Clinicians often discussed EOL wishes when a patient’s health status worsened” (p. 262)
Evangelista et al. (2014a)		“Participants who received additional palliative care (PC) services following the initial PC consultation were more likely to show improvements in fatigue (P<0.001), pain (P=0.044), anxiety (P=0.029), sense of well-being (P=0.035), dyspnea (P=0.008), and nausea (P=0.045)” (p. 77)
Evangelista et al. (2014b)		“A significantly greater proportion of participants who attended two or more palliative care consults showed increases in their activation levels (P <0.001) following the intervention compared to their counterpart” (p. 5).
Fendler et al. (2015)		“There is no clear consensus on the optimal timing and location of supportive care for patients with heart failure, except that early and iterative intervention is preferred” (p. 4)
Gadoud et al. (2014)		“However, in the heart failure group, a third of patients were not entered onto the palliative care register until the week prior to their death and nearly a half only in the six weeks prior to their death” (p. 6)
Gott et al. (2007)	Ability to predict the HF disease trajectory.	
Hauptman et al. (2008)	Ability to predict the HF disease trajectory.	
Kaasalainen et al. (2011)	Ability to predict the HF disease trajectory.	
Kavalieratos et al. (2014)	Ability to predict the HF disease trajectory.	“Among primary and palliative care providers, repeat hospitalizations over a short interval (eg, 3 in 6 months) suggested that palliative care might be appropriate” (p. 6) “…I think that the trigger to get [the palliative care service] involved was knowing that my patient was dying and that I didn’t have other medical options for them” (p. 6) “Palliative care providers discussed how networking and peer education have resulted in greater and earlier referrals by “winning over” previously skeptical colleagues” (p. 7)
LeMond & Allen (2011)	Ability to predict the HF disease trajectory.	“Although it is apparent that some aspects of palliative care should be considered early in the disease course of HF, the appropriate timing of end-of-life discussions and referral to hospice care is more problematic because of the variable nature of disease progression” (p. 4).
McKelvie et al. (2011)	Ability to predict the HF disease trajectory.	“We recommend that clinicians looking after HF patients should initiate and facilitate regular discussions with patients and family regarding advance care planning” (p. 328).
Michigan Quality Improvement Consortium (2012)	Ability to predict the HF disease trajectory.	“At the later stages, the facilitator should have experience with/knowledge of the patient’s specific condition” (p. 2). “Discussions should occur with a significant change in prognosis” (p. 3).
Seamark et al. (2002)	Ability to predict the HF disease trajectory.	

Author and Date	Barriers and Issues for Patients with Heart Failure Receiving End of Life Care	Role Clarification
Boyd et al. (2009)		“The heart failure nurse specialists had concerns about whether non-specialists could provide optimal clinical management and patient/carer education” (p. 769). “Patients and families highly valued a key health professional in a supportive, continuing relationship with them who could coordinate and plan their care proactively, offer personalized information, and foster self-management” (p. 769).
Davidson et al. (2004)		“The GP remains the primary case manager responsible for coordinating care and services” (p. 71)
Daley et al. (2006)		“One [participant] described how he felt no one ‘in authority’ was overseeing him, which caused him concern” (p. 598).
Fendler et al. (2016)		“The team cannot function effectively without a clear understanding of organizational and leadership structure” (p. 4) “ Early in disease progression, lead input is more likely to fall to a general practitioner or cardiology service, with palliative care consultation as needed” (p. 4) “In end-stage disease, palliative care specialists might take more central ownership of the patient’s care (p. 4)
Hanratty et al. (2002)		“…it should be the physician who’s interested, the general practitioner, the district nurse” (p. 583)
LaDonna et al. (2016)		“Each patient participant identified 2-19 team members, including health professionals and informal care providers” (p. 4)
Author and Date	**Barriers and Issues for Patients with Heart Failure Receiving End of Life Care**	**Team Functioning**
Brännström & Boman (2014)		“The between-group analysis of the age-adjusted delta-value of health-related quality of life (HRQL) from baseline to six months was significantly (p=0.02) better for patients in the PREFER group than for controls” (p. 1146)
Davidson et al. (2004)		“Evaluation by the study team revealed that the nurses caring for dying patients needed increased knowledge and further education about the palliative care approach” (p. 72)
Diop et al. (2017)		“The studies with improvement in the largest number of outcomes prioritized the integration of interdisciplinary HF and PC care” (p. 89)
Hauptman et al. (2008)	Uncertainties about the referral process to palliative care.	
Kaasalainen et al. (2011)		“Most participants described the importance of optimizing interprofessional collaboration to meet patient’s needs with a holistic perspective” (p.47) “The majority of the health professionals interviewed identified the need to build expertise in managing palliative care for patients with advanced HF” (p. 46)
McKelvie et al. (2011)		“Generic symptom relief strategies may be applied concurrently with heart failure management” (p. 328)

Yancy et al. (2013)		"Palliative and supportive care is effective for patients with symptomatic advanced HF to improve quality of life" (p. 1835)
Author and Date	**Barriers and Issues for Patients with Heart Failure Receiving End of Life Care**	**Conflict Resolution**
Ahia & Blais (2014)		"Identify and resolve conflicts" (p. 707).
Allen et al. (2012)		"In some cases, an intervention desired by a patient may appear discordant with the patient's stated goals and/or medical realities, and clinicians must explain why it is not warranted. This is particularly difficult in our national culture of entitlement and denial of morbidity and mortality" (p. 1944).
Author and Date	**Barriers and Issues for Patients with Heart Failure Receiving End of Life Care**	**Communication**
Allen et al. (2012)		"Shared decision making moves beyond informed consent. It asks that clinicians and patients share information with each other and work toward patient-centered decisions about treatment" (p. 1928).
Davidson et al. (2004)	Lack of communication.	
Lewis & Stephens (2005)	Lack of communication.	
De Vleminck et al. (2014)	Lack of communication.	
Hopp et al. (2010)	Lack of communication.	
Ivany & While (2013)	Lack of communication.	
Kaasalainen et al. (2011)	Lack of communication.	
McKelvie et al. (2011)		"The first step in the proposed framework is to assess patient readiness to participate in such discussions" (p. 327) "The longitudinal relationship with a trusted clinician, preferably with training in effective communication skills, may facilitate such conversations" (p. 327)
Wotton et al. (2005)	Lack of communication.	
Author and Date	**Barriers and Issues for Patients with Heart Failure Receiving End of Life Care**	**Patient/Client/Family/Community Centered-Care**
Kaasalainen et al. (2011)	Lack of patient understanding.	

Appendix C

Collaborating with palliative care teams to provide end of life care for patients with heart failure.

Factors Contributing Towards Collaboration	How Nurse Practitioners Can Collaborate to Provide End of Life Care for Patients with Heart Failure
Interprofessional Communication	1. Resolve poor communication • Utilize *Assessing Patient Readiness for EOL Discussions* • Utilize *The Framework for Conducting EOL Discussions with HF Patients* 2. Promote patient/client/family/community centered-care • Resolve misunderstandings • Annual heart failure review
Take Leadership	1. Address challenges with heart failure prognostication • Utilize the Seattle Heart Failure Model (SHFM) and the surprise question (i.e. asking oneself if you would be surprised if the patient passed away within the year) 2. Initiate early palliative care referrals • Engage in shared-decision making • Define an *early* palliative referral: when a patient has reached Stage II heart failure • Utilize the Supportive and Palliative Care Indicators Tool (SPICT) and the Gold Standards Framework (GSF) 3. Initiate advance care planning • Utilize the Advanced Heart Failure Personal Action Plan from the BC Heart Failure Network • Utilize My Voice: Expressing My Wishes for Future Health Care Treatment • Dedicate clinic time to initiate advance care planning discussions
Role Clarification	1. Identify palliative team members • Define the roles of individual team members 2. Consider designating a leadership role • Nurse practitioners can assume the lead once end of life is recognized then may consider a handover to palliative care
Promote Team Functioning	1. Use a holistic perspective • Consider utilizing the palliative advanced home care and heart failure care (PREFER) model

	2. Build expertise - Utilize *Managing Symptoms of Advanced Heart Failure* - Utilize the BC Heart Failure Network end of life clinical practice guidelines for heart failure symptom management - Utilize *Core Elements of the Chronic Care Model* 3. Resolve uncertainties about the referral process to palliative care - Refer patients early in the heart failure disease trajectory
Interprofessional Conflict Resolution	- Consider utilizing the six-step approach outlined by Ahia and Blais (2014) - Utilize steps to achieve conflict resolution (Discuss current therapies, Address emotional motivations, Clarify misunderstandings)