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Implementing Palliative Care Pre-Cardiothoracic Transplant

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Implementing Palliative Care Pre-Cardiothoracic Transplant
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Abstract

Palliative care is defined as a specialty of medicine that improves the quality of life of patients and family members facing a life-threatening illness, by providing early detection and prevention of pain, psychological, and other physical struggles. Patients diagnosed with diseases such as congestive heart failure or lung disease will face an ongoing list of problems that impacts their quality of life, yet most do not receive the proper tools to manage their disease until the last stages of their life. Implementing palliative care at the initial diagnosis of a chronic cardiothoracic disease improves precision of patient-centered goals, symptom management, and overall quality of life for the patient.

Implementing Palliative Care Pre-Cardiothoracic Transplant **Cardiothoracic Diseases**

The diagnosis of a chronic cardiothoracic disease such as congestive heart failure (CHF), or lung diseases like idiopathic pulmonary fibrosis (IPF) or chronic obstructive pulmonary disease (COPD), requires a patient to decide treatment options that often focus on life-prolonging measures, even cardiothoracic transplant. With the diagnosis of a chronic illness, medical specialties such as cardiology, pulmonology, and cardiothoracic surgery are immediately employed. Under most circumstances, palliative care is rarely integrated until the patient's status is deteriorating or there is a failure to thrive.

The World Health Organization (2018) 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, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care provides relief from pain and other symptoms, emphasizes advanced care planning and medical treatment based on patient wishes, and uses an interdisciplinary approach to address all needs of the patient and family. Palliative care is split into eight domains that focus on 'whole person care' that acknowledges nonmedical facets of suffering when diagnosed with a serious or life-threatening illness (Anderson, Frazer, & Schellinger, 2018). These domains ensure that a patient is taken care of physically, psychologically, socially, spiritually, culturally, ethically, and at the time of death, while simultaneously ensuring that all necessary medical specialties are involved in patient care.

Integrating palliative care at the initial diagnosis of a life-threatening cardiothoracic disease would allow treatment options to be based on patient-centered goals of care, focus on symptom management, and improve quality of life for the patient. Since heart failure impacts nearly 6 million people in the United States and remains one of the leading causes of hospitalization and health care expenditures it is important to focus on heart failure and how these patients' lives will be impacted (Tanner, Fromme, & Goodlin, 2011).

In order to recommend an integrated care model for a patient with the diagnosis of a chronic disease, it is important to understand how symptoms will impact the patient, how symptoms can be managed, and what can be done to optimize a patient's quality of life based on their personal goals and the domains of palliative care.

Congestive Heart Failure

Congestive heart failure is defined as the inability of the heart to keep up with the demands on it, with failure of the heart to pump blood with normal efficiency. The heart is then unable to provide adequate blood flow to organs such as the brain, kidneys, and liver. Heart disease and CHF are difficult illnesses due to their complex symptom burden. CHF symptoms include: dyspnea, cardiac asthma, poor blood circulation, edema, and enlargement of the heart that leads to weakness, decreased blood flow to accessory organs, dizziness, and a decrease in overall function. These symptoms prevent patients from performing daily activities as they once did and often times impacts quality of life.

Lung Disease

Lung disease is defined as any problem in the lungs that prevents a patient from working properly, whether it may be an airway disease (chronic obstructive pulmonary disease), lung tissue disease (cystic fibrosis), or lung circulation disease (pulmonary hypertension). Symptoms

of lung disease often include: coughing, wheezing, frequent respiratory infections, fatigue, and poor blood circulation. Mozes (2017) reports from 1980 through 2014, more than 4.6 million Americans died from a range of chronic respiratory illnesses (Mozes, 2017). The risk of death from chronic respiratory diseases rose 31% over the past 35 years and nearly 7% of all deaths in America are due to chronic respiratory diseases (Mozes, 2017). Factors for the increased rates are multifactorial but the significant increase in rates suggests that greater attention be paid to lung diseases. Currently, lung transplant candidates are rarely referred to palliative care unless they are deemed ineligible for transplant. End of life care is often aggressive and not based on comfort (Colman, Singer, Barua, & Downar, 2015).

Commonly, palliative care is associated with hospice and dying. Physicians often make this assumption and postpone palliative care intervention as long as possible. However, the symptoms and statistics of chronic cardiothoracic disease suggest that integrating palliative care with cardiothoracic disease in its early stage is necessary as patients often have prolonged periods of stability between exacerbations of their symptoms (Tanner, Fromme, & Goodlin, 2011). Integrating palliative care at the initial diagnosis of a chronic cardiothoracic disease improves precision of patient-centered goals, symptom management, and overall quality of life for the patient.

Choices After Diagnosis

After being diagnosed with cardiovascular disease or idiopathic pulmonary fibrosis, for example, the patient and family is often overwhelmed with information and the potential treatment options following their diagnosis. Subsequent heart disease treatment options often include procedures such as coronary artery bypass graft, insertion of ICD pacemakers, ventricular assist devices, extracorporeal membrane oxygenation (ECMO), heart transplant or potentially the use of only medications such as beta-blockers or diuretics. These treatment options range from mild to highly aggressive depending on the condition and wishes of the patient and the family.

Lung disease follows a similar pattern of mild to aggressive treatment options. Common treatment options include breathing treatments and antioxidants to slow the rate of lung decline in hopes of improving symptoms such as dyspnea, hypoxia, and weakness. Although those treatments may postpone the rate at which lung disease progresses, "lung transplantation remains the only treatment for most non-malignant end-stage lung disease" with the transplant candidates carrying a high symptom burden physically and psychologically (Colman, Singer, Barua, & Downar, 2015).

Medical facilities traditionally recommend heart and lung transplantation when other medical treatments no longer help. Medical programs currently believe the right time to proceed with transplantation is when it is felt that the patient would live longer with a transplant than with the heart or lung disease. Although this seems intuitive we must consider the treatment imperative- "defined as the perceived need by physicians and patients to provide interventions. The treatment imperative is driven by physicians' desires to offer treatment and patients feeling bound to not refuse treatment" (Santivasi, Strand, Mueller, & Beckman, 2017). Doctors are required to honor the Hippocratic oath in their practice; to do no harm and to treat the ill to the best of one's ability. Physicians are educated and trained to save patients' lives. The quality of life may at some point be compromised at the cost of prolonging someone's life. Patients feel intrigued to try new experimental surgeries or treatments that are considered life-prolonging but often times forget their personal wishes and goals of care or are unaware of the side effects.

Physicians take their oath to save and heal, but they may forget that they should do what is best for the patient, which may or may not be performing surgery or providing life-prolonging treatment. Similar to the treatment imperative is the organ transplant imperative which is "the perceived obligation to proceed with transplant and avoid end-of-life planning even in situations where the patient is experiencing poor quality of life and low likelihood of meaningful survival" (Santivasi, Strand, Mueller, & Beckman, 2017). With considerations of the treatment and organ transplant imperatives, it is important to have conversations regarding goals of care with the patient and family. The conversation should not occur once and be forgotten about. Goals of care and expectations from the patient should be addressed at the initial diagnosis and continue as the patient progresses with their disease to ensure that treatment, or lack of treatment, is what is best for the patient.

Chronicity of Disease

Cardiothoracic diseases are complex due to their chronic nature with a slow and steady decline in function. Patients dealing with a chronic, or life threatening illness will experience what Robin Rone (2011) refers to as the four components of pain, better explained in figure 5 (Rome, Luminais, Bourgeois, & Blais, 2011). The four components include physical symptoms, anxiety over the time to come, interpersonal problems, and not accepting that death may be approaching. Patients dealing with heart failure face a shortened lifespan and a chronic decline in function that may not be visible until the onset of an acute exacerbation (Tanner, Fromme, & Goodlin, 2011). It is difficult to prepare for and treat these acute bouts of CHF or lung disease without palliative care and the advanced care planning the specialty provides. When an acute event occurs, sudden decisions by the patient or patient's family member are made during stressful periods. These decisions often do not focus on the patient's goals of care but only what is necessary in the moment. In these circumstances difficult decisions are often postponed to focus on the present medical issue.

Patients awaiting a transplant experience high levels of anxiety due to the uncertain amount of time on the organ donor list. The demand for organs far exceeds the supply, causing patients to be on waitlists for years potentially. As of October, 2018 the Gift of Life states 156 Michigan residents are awaiting heart transplants and 99 Michigan residents are waiting for lungs. While waiting for a transplant, a patient's condition may wax and wane so it is important to address goals of care and patient wishes even before a transplant because patients may never reach the destination of a transplant. Discussing goals of care prior to transplant helps navigate the uncertain territory of the waitlist.

Patients should be guided to appreciate that certain life-sustaining measures such as extracorporeal cardiopulmonary life support (ECLS) are not life saving but life prolonging until the next option arrives. ECLS is a variation of cardiopulmonary bypass that maintains oxygenation for days to weeks in patients with life threatening respiratory or cardiac failure. Patients may not understand they may not be guaranteed a transplant once placed on the list, and even if the patient receives a transplant, it may not be beneficial. Aggressive end of life care such as ECLS is associated with worse patient quality of life and higher rate of anxiety in bereaved family members (Colman, Singer, Barua, & Downar, 2015). Even when patients with idiopathic pulmonary fibrosis are not being considered for transplant, a high proportion die in the ICU, with relatively few are seen by a palliative care specialist.

Discussing goals of care and expectations of treatment prior to transplant helps medical providers and patients align their expectations and base treatment options accordingly to provide

a better understanding of the uncertain road associated with cardiothoracic disease and transplantation.

Lack of Palliative Care Education

Patients often experience unclear expectations when a cardiothoracic transplant is suggested as mentioned above. Time on the waitlist may take a toll on the patient and their family. However, even when the relief of palliative care (PC) is offered when the patient begins their chronic deterioration, a negative connotation is associated with the term. Palliative care is too closely associated with hospice and dying in today's society. When a patient or family member hears the suggestion of palliative care, they immediately associate the term with hospice and dying in the near future, or do not know what PC entails. Figure 2 evaluates how aware consumers are of the term palliative care; 92% are unfamiliar with the actual purpose of PC. It should be made clear that palliative care and hospice are separate specialties of medicine with similar goals including improving and, or maintaining the patient's quality of life (QOL).

Barriers to early evaluation of care preferences in lung transplant patients include the perception that these discussions would disqualify patients from disease-directed therapies. With this in mind, some providers and patients believe that PC is incompatible with transplantation and that palliative treatments should be held until the patient's final hours to not ruin the chance for transplant (Santivasi, Stand, Mueller, & Beckman, 2017). Physician focus groups showed that physicians are often very hesitant to recommend palliative care as anything other than "end of life care" or "comfort care", which would technically be considered hospice care, even though physicians are not making this distinction (McInturff, Harrington, 2011). A survey of transplant centers also indicated that patients believed if they engaged in palliative care they would feel abandoned, or that their quality of care would be insufficient (Santivasi, Stand, Mueller, & Beckman, 2017). In addition, patients expressed a concern with opioid dependency in association with palliative care, although this has been proven not to be an issue (Colman, Singer, Barua, & Downar, 2015). The lack of palliative care education amongst patients and providers alike makes it difficult to suggest palliative care as a method of improving quality of life. Thus, an issue is created where a trigger event must occur in order to initiate palliative care when the patient is in their final stages of life, "perpetuating the false dichotomy of palliative care versus (rather than palliative care plus) life-prolonging therapy" (Kavalieratos et al., 2017). It has been suggested that using different terms when describing palliative care may be beneficial. For example, using terms such as 'serious illness' instead of 'terminal illness' gives the patient hope that there is still opportunity in the face of chronic illness. Education plays a large role in the acceptance and integration of palliative care into everyday medicine. Quality of life can be improved for both patients and families with a better understanding of palliative care.

General Benefits/ Purpose of Palliative Care

Palliative care is an interdisciplinary approach and clinical subspecialty that focuses on improving QOL and reducing suffering experienced among patients with serious illness and their families (Kavalieratos et al., 2017). To be clear, quality of life is the concept used when discussing the implications of a serious medical condition. Doctors, family members, and others can have an opinion on the patient's quality of life, but only the patient themselves are able to truly determine their quality of life and what it would look like. One person may only care to be self-sufficient as long as possible, while another may want to walk their daughter down the aisle and be happy with whatever happens subsequent to that event. Each person has different goals

and this makes quality of life multidimensional and very personal. Quality of life considers physical, social, psychological, and spiritual wellbeing ("Quality of Life," 2012). Symptom burden heavily dictates quality of life. To understand the magnitude of heart failure, it has been stated that "advanced heart failure patients face a symptom burden comparable to that of advanced cancer patients" (Tanner, Fromme, & Goodlin, 2011).

Management of Complex Symptom Burden. Palliative care puts emphasis on symptom and pain management through medications and therapies that primary physicians would often not consider. PC is able to manage complex symptom burden experienced by chronic heart and lung disease patients. LVAD patients experience bleeding, infection, device thrombosis, and cerebrovascular events that can negatively impact their QOL and place a large burden on family members, physically and psychologically. Joint Commission and Centers for Medicare and Medicaid Services (CMS) determined that PC should be incorporated into LVAD destination therapy (Nakagawa, Yuzefpolskaya, Colombo, Naka, & Blinderman, 2017). Patients in end-stage lung disease awaiting transplant experience physical, psychological, and emotional symptoms including dyspnea, cough, anxiety, depression, and insomnia (Freeman et al., 2016). The integrative approach PC provides would help manage symptoms and propose new ways to treat complex symptoms.

Economic Relief. Along with the physical and psychological stress heart failure and lung disease place on patients and families, there is also a large financial burden associated with these diseases. Heart failure management places a large financial burden on families, health care systems and society. Dio Kavalieratos states that "direct medical costs of HF are projected to be >\$77 billion by 2030, a 215% increase from current spending" (Kavalieratos et al., 2017). In part, the massive expense can be attributed to recurring hospital admission associated with lack of advanced care planning in HF and lung disease patients. Although doctors and patients tend to avoid end of life (EOL) conversations and the possibility of death, patients who did engage in these conversations had enhanced hope (Nakagawa, Yuzefpolskaya, Colombo, Naka, & Blinderman, 2017). Patients who expressed their wishes under PC support would be able to minimize unnecessary hospitalizations, thus decreasing costs and excess stress.

Improved Patient Outcomes. Palliative care is able to manage a complex symptom burden associated with heart failure and lung disease, as well as improve patient outcomes. A 2010 study reported that lung cancer patients receiving early palliative care had less depression, improved quality of life, and survived 2.7 months longer (Center to Advance Palliative Care). A large proportion of end-stage lung disease patients (lung transplant candidates and recipients in particular) die in a critical care environment, receiving aggressive care that is not focused on comfort (Colman, Singer, Barua, & Downar, 2015). Palliative care would help to direct the patient's medical care in the direction the patient and family deemed best. Institutions such as the American College of Chest Physicians (ACCP) and American Thoracic Society (ATS) have both emphasized the importance of palliative and end of life care (EOLC) for symptomatic patients with pulmonary disease at any stage of illness (Colman, Singer, Barua, & Downar, 2015).

When to Begin Palliative Care

Introducing the topic of palliative care and the conversation of advanced care planning is often one of the more difficult tasks doctors admit to in their practice, quite possibly a reason palliative care is underutilized. New studies have suggested that the best way to manage heart failure symptoms is to treat the underlying heart failure condition (e.g., relieving dyspnea by addressing fluid overload) (Kavalieratos et al., 2017). The approach mentioned is an example of

how heart failure and palliative care can interface in the early stages of a diagnosis to help alleviate a patient's symptom burden and worries of their disease. At the initial diagnosis of heart or lung disease, prognostication should be used to have clear algorithms and checklist in place to manage care following diagnosis and determine if a patient is ready for a cardiothoracic transplant. Included on the initial checklist should be the consult of palliative care. In this manner, the PC team is able to meet with the patient, discuss goals of care, possible treatment plans reflecting those goals or care, and support to patients deciding if cardiothoracic transplant is in the patient's best interest. The use of such checklists could alleviate the transplant imperative, unnecessary stress, and hospital visits for the patient.

In addition to using checklists and algorithms to standardize when patients should begin palliative care, PC has shifted to outpatient consultations that would allow early integration of services. Outpatient clinics suggest that a patient is still battling with a disease, but symptoms have not progressed far enough to require hospitalization; this timing provides "an ideal opportunity to integrate palliative care into a transplant program" (Wentlandt et al., 2016). The patient and family member may feel less overwhelmed outside of a hospital where they feel they may be dying. Outpatient palliative care consultations allow clear conversations to be made, with the intent of advanced care planning and discussion of the realistic options ahead.

The Transplant Palliative Care Clinic (TPCC) in Toronto, Canada is an outpatient clinic that takes patients with any advanced disease as evaluated by the transplant program, and performs palliative care consults with no limitation on prognosis, status on the waiting list, or being pre- or post-transplantation (Wentlandt et al., 2016). The initial consultation lasts about 60-90 minutes, includes a chart review, history, and assessment. Additionally, a symptom assessment survey is completed at each appointment, with additional referrals being made as necessary. The TPCC is allowing patients to have a patient-centered care plan that manages symptoms and allows an integrative approach to be made regardless of the patient's progression in their disease. The patient's status on the wait list is not compromised because of their PC assistance as patients and physicians often fear- the only difference is the patient's QOL is improved with palliative care consultations (Wentlandt et al., 2016). Figure 3 suggests starting palliative care at the initial diagnosis and tailoring the patient's treatment to fit their goals, which may change as the disease progresses. Table 1 provides insight into the timing related to referring a patient to primary palliative care, or specialized palliative care resources. Primary PC should be initiated at the initial diagnosis of cardiothoracic disease and as symptoms progress as shown in the table, specialized care can be escalated (Kavalieratos et al., 2017).

Integration of Palliative Care

Saying that palliative care is important and worthy is not enough. The challenge remains in how PC is integrated, and how it will supplement chronic disease and/or a potential cardiothoracic transplant. Accepting the outlook that palliative care is 'preparedness planning' for patients who are focused on improving shifts the connotation away from dying. It has been suggested by Dr. Craig Tanner that preparedness planning should be proposed at the initial diagnosis of heart failure (Tanner, Fromme, & Goodlin, 2011). In an effort to do this, palliative care has been integrated in outpatient clinics, as mentioned previously. Additionally, interdisciplinary primary care models for older adults with chronic illnesses are now of particular interest. Four features of a care model trialed by Washington University's Care Coordination Program included: comprehensive assessment of the patient's health conditions, treatments, behaviors, risks, supports and resources, evidence-based care planning and monitoring to meet

the patient's health related needs and preferences, promotion of patients' and family caregivers' active engagement in care, and coordination and communication among all professionals engaged in a patient's care (McCarthy, Ryan & Klein, 2015). Integrating a care model of this nature offers to achieve the "triple aim" that reduces costs while improving the patient's health and care experiences. A high need patient in this context would be a chronic or terminal illness patient with either CHF, IPF, or lung cancer with high costs associated with frequent hospital readmissions due to a lack of care planning or proper expectations of potential outcomes following procedures such as an LVAD or cardiothoracic transplant.

If palliative care were to intervene earlier in these high-risk, high-cost patients' diagnoses, the extra resources could be placed in improving their QOL and decrease costs, allowing a return on investment (ROI) that palliative care provides. The average cost for one night of treatment in an intensive care unit is \$4000 (Winters, 2013). With palliative care on-boarded, there is potential to minimize these admissions with advanced care planning. Tables 2-5 highlight the chance of hospital admissions with PC. The results are not significant. However, clinical trials with PC are still novel, leaving promise for future growth.

Similar to a checklist at the time of diagnosis, several doctors trialed a pre-VAD evaluation for patients in destination therapy (would use device until death) or those with bridge to transplantation. The pre-VAD evaluation "aimed to test the feasibility of PC intervention to elucidate patients' goals and values in LVAD therapy in both destination therapy (DT) and bridge to transplant (BTT)" ((Nakagawa, Yuzefpolskaya, Colombo, Naka, & Blinderman, 2017). The palliative care evaluation was mandatory and addressed patient comfort, patient and family understanding of LVAD therapy, patient goals and expectations, spiritual needs, possible complications and unacceptable conditions, as well as decision making. After the evaluation, family awareness of acceptable conditions for a patient increased from 33% to 58%, being statistically significant, $p < 0.01$ ((Nakagawa, Yuzefpolskaya, Colombo, Naka, & Blinderman, 2017). Another study found similar results, finding that after a PC consultation, six patients requested their resuscitation orders be changed from full code to DNR (Colman, Singer, Barua, & Downar, 2015). Knowledge of effective palliative care routes made some patients realize their goals could be achieved without life-prolonging measures and treatments. Facilities utilizing palliative care on a regular basis report that integration of palliative care prior to ventricular assist device placement can help prepare patients and families for the difficult process of discontinuing VAD support (Colman, Singer, Barua, & Downar, 2015). These studies demonstrate that early intervention through consultations and evaluations help patients identify their desires in the face of illness as well as reduce emotional and financial stress as difficult decisions arise later in the course of illness.

Destination with Early Palliative Care

Clinical trials implementing palliative care in the early stages of heart and lung disease are scarce because the research is still new. The lack of education and push towards the treatment imperative make it difficult for patients and physicians to accept palliative care, but the studies that do integrate palliative care early in a patient's treatment plan are promising and show statistical significance. The Palliative Care in Heart Failure (PAL-HF) clinical trial provided an interdisciplinary palliative care intervention in advanced HF patients that consistently showed greater benefits to QOL, anxiety, depression, and spiritual well-being compared to usual care alone. A study performed in 2010 determined patients assigned to early PC had fewer depressive symptoms ($p=0.001$) compared to standard care patients and the median survival was longer

amongst PC patients as well ($p=0.002$) (Temel et al., 2010). Temel (2010) reports data in figure 4 indicating that early palliative care intervention increased life expectancy by an average of 3 months. Sidebottom (2014) found similar results in her study where QOL scores increased 12.92 points in the intervention compared to 8 points in the control group that did not receive PC intervention ($p<0.001$) (Sidebottom, Jorgenson, Richards, Kirven, & Sillah, 2014). Symptom burden between test subjects and controls also had statistical significance ($p<0.001$) (Sidebottom, Jorgenson, Richards, Kirven, & Sillah, 2014). Kavalieratos (2017) reports findings from a 2015 trial that compared the impact of inpatient consultation by a palliative care team versus usual care for patients hospitalized for acute HF. Data suggest statistically significant improvements for patients receiving inpatient PC consultations, including QOL, symptom burden, and mood" (Kavalieratos et al., 2017). Studies such as they indicate the benefit of integrating palliative care early in a patient's diagnosis.

A common misconception about palliative care and symptom management include the prescription of opioids and benzodiazepines for symptom management. Both physicians and lung transplant candidates often avoid such medications due to concern that they may compromise a patient's eligibility for transplant (Colman, Singer, Barua, & Downar, 2015). However, several clinical trials determined that "there were no episodes of clinically important opioid toxicity or respiratory depression, and there was a trend toward increased exertion during exercise sessions post-opioid versus pre-opioid" (Colman, Singer, Barua, & Downar, 2015), suggesting that opioids prescribed to alleviate symptoms may improve quality of life without compromising transplant eligibility. From a retrospective cohort study, 8 lung transplant recipients (33%) co-managed with palliative care did not receive CPR at the time of death, as dictated by palliative care planning (Colman, Singer, Barua, & Downar, 2014). Small details such as these may seem insignificant. However, it is shown that when patient's wishes at the time of death were honored the bereavement of family members was improved (Anderson et al., 2018). Family members are able to reflect on their loved one's legacy and find solace in knowing their wishes were honored.

Although physicians are reluctant to integrate palliative care into their patient's care, "heart failure/ transplant team physicians who requested assistance with symptom management, clarification of goals of care, and end-of-life care, viewed PC integration as beneficial to the patient. Improved efficiency of HF/ transplant team was reported" (Schwarz et al., 2012). Palliative care consultations and intervention helped dying lung transplant patients avoid aggressive care and the ICU environment at the end of life (Colman, Singer, Barua, & Downar, 2015). By limiting the number of ICU visits, family members decrease the excessive cost of hospitalizations, as well as the uncertain stress hospitals place on families and patients. Palliative care may seem to be an additional cost, but there is a return on investment when considering unnecessary medical treatment. For example, "patients enrolled in Medicaid at 4 New York state hospitals who received palliative care incurred \$6,900 less in hospital costs than a matched group receiving usual care (Center to Advance Palliative Care). Palliative care consultations in another study done by CAPC resulted in reductions of \$1,700 in direct costs per admission for live discharges and \$4,900 per admission when the patient died in the hospital (Morrison et al., 2008). When the costs are extrapolated, the result is a saving of more than \$1.3 million for a small hospital, and \$2.5 million for an average sized medical center. Cost analysis of early palliative care integration is still underdeveloped with complex interactions between costs of care and diagnosis (e.g. cancer/ non-cancer distinctions) but these numbers show promise towards reducing costs in an aging population (Smith, Brick, O'Hara, & Normand, 2014). Integrating

palliative care early may also reduce costs by reducing the number of hospital admissions. Further research is required to determine exact cost savings.

Palliative care is designed to look at a patient in the most holistic sense with domains currently categorized into the following groups: spiritual, social, psychological, physical, ethical, cultural, end of life aspects. These categories focus on goals of care that best influence the patient, family, and potentially the health care system with the reduction of costs and high-risk patients within hospital settings. Potential lies in adding a financial and legacy/bereavement domain to the field, as they are already goals that lie within the principles of palliative care. The goal of integrating palliative care at an early stage encompasses these ideas and allows a smooth transition through arguably the most daunting time in a patient's life. Palliative care aids in allowing the dying process to seem more normal. Families are able to better prepare for death of their loved one knowing their wishes were met, and a plan was in place. Palliative care focuses on these ideals and the domains to improve the precision of patient-centered goals, symptom management, and overall quality of life for the patient.

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Tables/ Figures

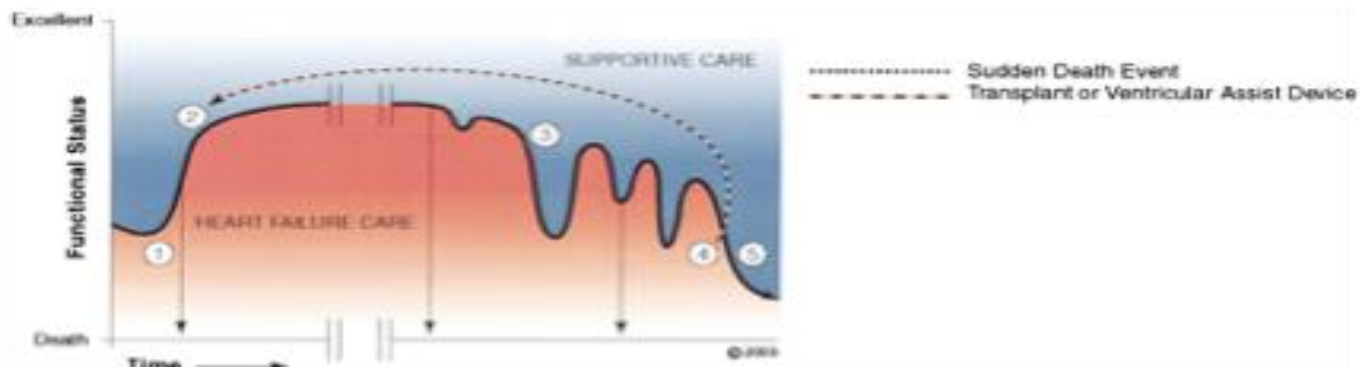


Figure 1. Demonstrating the waxing and waning condition of a heart failure patient awaiting a transplant (Bayoumi, Sheikh, & Groninger, 2017).



*Data from a Public Opinion Strategies national survey of 800 adults age 18+ conducted June 5-8, 2011.

Figure 2. Consumer Awareness About Palliative Care. Approximately 92% of consumers in the health care industry either misunderstood, or did not understand the purpose of palliative care. With greater education, the distinction between palliative care and hospice can be made and quality of life of many could be improved (McInturff, Harrington, 2011).

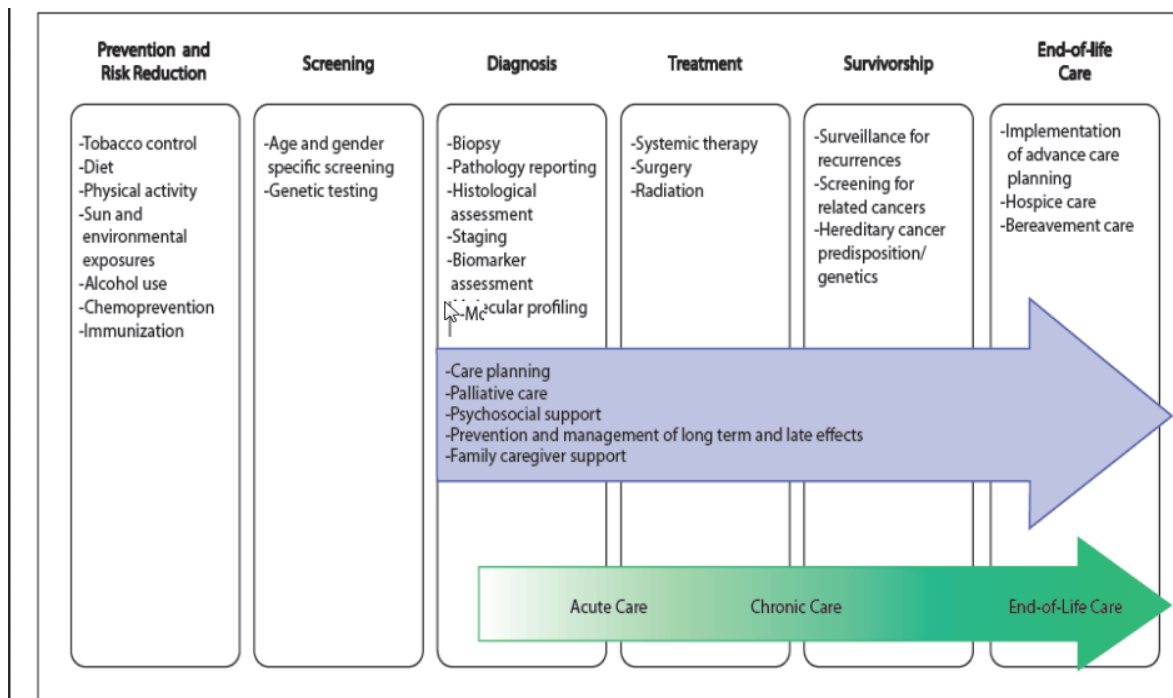


Figure 3. Suggested time to initiate palliative care and how palliative care will progress through the remainder of the patient's life (Kirch, 2011).

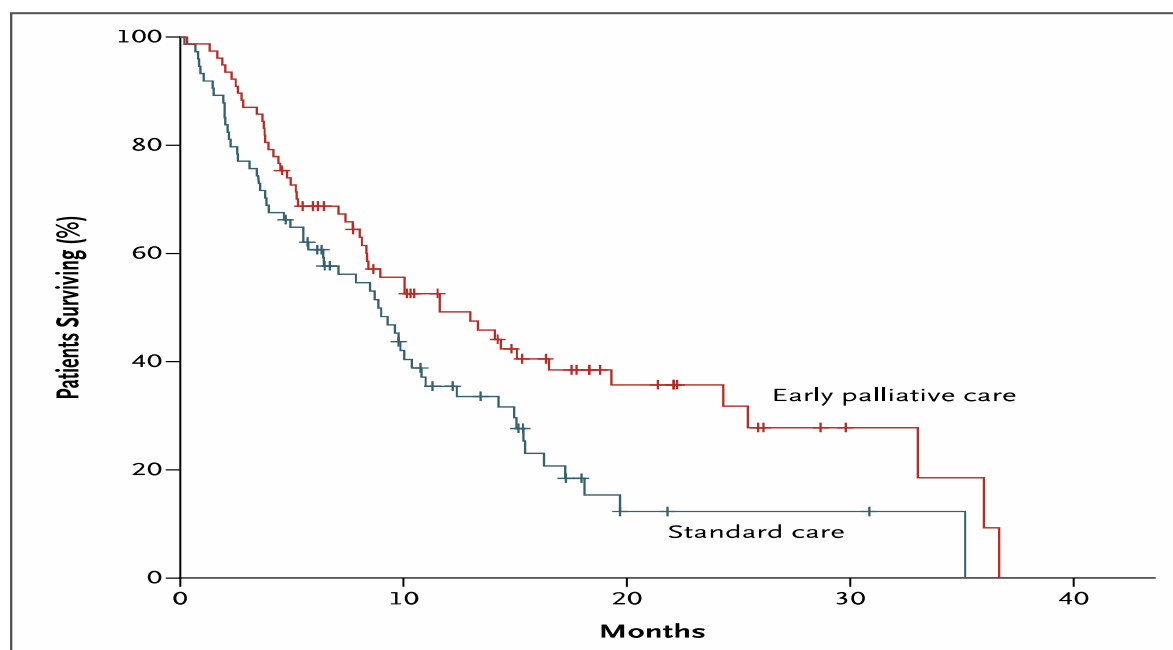


Figure 4. Kaplan- Meier Estimates of Survival According to Study Group. Median estimates of survival were as follows: 9.8 months in the entire sample (151 patients), 11.6 months in the group assigned to early palliative care (77 patients), and 8.9 months in the standard care group (Temel et al, 2010).

P	Physical problems, often multiple, must be specifically diagnosed and treated.
A	Anxiety , anger, and depression are critical components of pain that must be addressed by the physician in cooperation with other healthcare professionals.
I	Interpersonal problems, including loneliness, financial stress, and family tensions, are often interwoven into the fabric of a patient's symptoms.
N	Not accepting approaching death, a sense of hopelessness, and a desperate search for meaning can cause severe suffering that is unrelieved by medications.

Figure 5. Symptoms experienced by patients diagnosed with a chronic or terminal illness that may or may not be dying (Rome, Luminais, Bourgeois, & Blais, 2011).

Table 1. Primary Palliative Care Versus Specialty Palliative Care for Patients with Heart Failure and Their Families. Criteria for when to refer to primary palliative care versus specialty palliative care (Kavalieratos et al., 2017).

	Domain	PPC	When to Refer to SPC
Symptom management	Shortness of breath	<ul style="list-style-type: none"> Maximize HF therapies to relieve congestion 	<ul style="list-style-type: none"> Debilitating refractory dyspnea despite PPC interventions
	Pain	<ul style="list-style-type: none"> Determine etiology of pain and treat accordingly Maximize antianalgesic medications and recommend activity modification for analgesic pain Refer to physical therapy, if appropriate Refer to multidisciplinary pain teams and pain specialists, if appropriate 	<ul style="list-style-type: none"> Pain refractory to PPC interventions
	Depressed mood	<ul style="list-style-type: none"> Distinguish adjustment disorder from depressive disorder Treat adjustment disorder with supportive counseling or referral for psychotherapy Treat depressive disorder with referral to cognitive-behavioral therapy and consider medication management; consider referral to psychiatrist/psychologist 	<ul style="list-style-type: none"> Symptoms of major depressive disorder such as incapacitating hopelessness, anhedonia, or suicidality requiring medical management
	Anxiety	<ul style="list-style-type: none"> Treat mild anxiety with referral to psychologist for help with relaxation techniques and psychotherapy or initiation of anxiolytic medication (if appropriate) Refer to psychiatrist for severe anxiety 	<ul style="list-style-type: none"> Debilitating anxiety or panic symptoms that develop at the time of or shortly after HF diagnosis that prevent patient from participating in regular activities
	Nausea	<ul style="list-style-type: none"> Adjust HF therapies Determine etiology of nausea (e.g., gastroparesis vs. supratherapeutic drug levels or electrolyte abnormalities) 	<ul style="list-style-type: none"> Ongoing symptoms despite PPC interventions
	Fatigue	<ul style="list-style-type: none"> Optimize HF therapies Refer to cardiac rehabilitation Evaluate and treat for insomnia Evaluate for sleep disordered breathing, if indicated 	<ul style="list-style-type: none"> Ongoing symptoms despite PPC interventions
	Insomnia	<ul style="list-style-type: none"> Educate on sleep hygiene Educate on relaxation techniques Refer for cognitive-behavioral therapy 	<ul style="list-style-type: none"> Ongoing symptoms despite PPC interventions
Communication and advance care planning	Discussing code status	<ul style="list-style-type: none"> Basic education and discussions about implications of CPR 	<ul style="list-style-type: none"> Patients with misunderstandings of illness and prognosis after CPR
	Advance care planning, including decisions to withdraw life-sustaining therapies	<ul style="list-style-type: none"> Engage patient and family in discussions to elicit goals of care and identify surrogate Identify preferences regarding cardiac device deactivation (if appropriate) 	<ul style="list-style-type: none"> Patients with misunderstandings of their illness and prognosis Patients and families who are in disagreement about the patient's end-of-life choices Patient or family are in disagreement about the chosen surrogate or if patient is ambivalent about choice Patients and/or surrogates who are in disagreement about the treatment that best matches patient's goals and values Surrogates who lack insight into patient's goals and values
	LVAD preparedness planning/transplant decisions	<ul style="list-style-type: none"> Involve palliative care specialist (per TJC recommendations) 	<ul style="list-style-type: none"> SPC can review treatment options with patient
	Request for assisted suicide	<ul style="list-style-type: none"> Refer to specialist level palliative care or ethics consultation 	<ul style="list-style-type: none"> SPC to navigate complex request and explore other options
Psychological support	Patient support	<ul style="list-style-type: none"> Supportive listening Refer to social work or community resources (if available) 	<ul style="list-style-type: none"> Refer to SPC when needs exceed the expertise of HF social worker, especially around issues of end-of-life care, such as counseling parents on how to talk with their children
	Caregiver support	<ul style="list-style-type: none"> Supportive listening Refer to social work or community resources (if available) 	<ul style="list-style-type: none"> Patient's needs exceed the expertise of the HF social worker, especially if caregiver has significant needs or the patient and caregiver are in conflict
Care coordination		<ul style="list-style-type: none"> Communicate with other health care providers Refer for home hospice for patients with good support at home and without complex medical or social needs 	<ul style="list-style-type: none"> Complex hospice or home care referral for patients who require placement in facilities with need for complex medical management (e.g., palliative home intropes)

Adapted with permission from Gelfman et al. (70).

CPR = cardiopulmonary resuscitation; HF = heart failure; LVAD = left ventricular assist device; PPC = primary palliative care; SPC = specialty palliative care; TJC = The Joint Commission.

Table 2. Summary of Existing Trials of Inpatient Specialty Palliative Care in Heart Failure. Results from previously performed clinical trials implementing PC in HF (Kavalieratos et al., 2017).

Study (Ref. #), Year (Country)	Patient Population*	Intervention (Participants Randomized)	Control (Participants Randomized)	Results	Risk of Bias	
					Subjective	Objective
Hopp et al. (49), 2016 (U.S.)	Acute HF, 1-yr mortality risk of $\geq 33\%$, and/or NYHA functional class III-IV (mean age: 68 yrs)	Inpatient specialist consultation from a multidisciplinary team (physician, nurse practitioner, chaplain, social worker) conducted clinical interview(s), assessing symptoms, goals of care and post-treatment location desires, and advance care planning (n = 43)	Usual care (n = 42)	<i>Hospice utilization/ACP</i> Composite outcome: NS; difference between groups: 9.3% (95% CI: -11.8% to 30.0%)	High	High
Sidebottom et al. (48), 2014 (U.S.)	Acute HF (mean age: 73 yrs)	Specialty multidisciplinary palliative care consultation assessing physical and emotional symptoms, spiritual, and social aspects of care (n = 116)	Usual care (n = 116)	<i>QoL</i> Minnesota Living with Heart Failure Questionnaire: Improved, mean difference: 3.06 points (95% CI: 2.75-3.37) <i>Symptom burden</i> ESAS: Improved total symptom burden, mean difference: 4.31 points (95% CI: 4.00-4.62) <i>6-month mortality</i> NS; HR: 1.90 (95% CI: 0.88-4.09) <i>30-day hospital readmission</i> NS; HR: 1.43 (95% CI: 0.5-4.1) <i>Hospice use within 6 months</i> NS; HR: 1.60 (95% CI: 0.58-4.38) <i>ACP within 6 months</i> Improved; HR: 2.87 (95% CI: 1.09-7.59) <i>Mood</i> PHQ-9: Improved; mean difference: 0.72 (95% CI: 0.41-1.03)	High	High

*Patient population details the indication for palliative care. All comparisons stated as intervention versus control.

ACP = advance care planning; CI = confidence interval; ESAS = Edmonton Symptom Assessment Scale; HF = heart failure; HR = hazard ratio; NS = not significant; NYHA = New York Heart Association; PHQ-9 = Patient Health Questionnaire 9; QoL = quality of life; U.S. = United States of America.

Table 3. Summary of Existing Trials of Outpatient Specialty Palliative Care in HF. (Kavalieratos et al., 2017)

Study (Ref. #), Year (Country)	Patient Population*	Intervention (Participants Randomized)	Control (Participants Randomized)	Results	Risk of Bias	
					Subjective	Objective
Rogers et al. (43), 2017 (U.S.)	Hospitalization for HF in past year and ESCAPE score ≥ 4 indicating >50% risk of 6-month mortality. (mean age: 71 yrs)	Interdisciplinary NP-led specialty palliative care intervention concomitant with usual HF management. Intervention foci included physical and emotional symptom management, spiritual concerns, and advance care planning (n = 75)	Usual care (n = 75)	<p><i>QoL</i></p> <p>KCCQ: Improved at 6 months, mean difference: 9.49 points (95% CI: 0.94 to 18.05; $p = 0.03$)</p> <p>FACIT-Pal: Improved at 6 months, mean difference: 11.77 points (95% CI: 0.84 to 22.71; $p = 0.035$)</p> <p><i>Mood</i> HADS depression: Improved at 6 months, mean difference: -1.94 points (95% CI: 3.57 to -0.31; $p = 0.02$)</p> <p>HADS anxiety: Improved at 6 months, mean difference: -1.83 points (95% CI: -3.64 to -0.02; $p = 0.048$)</p> <p><i>Spiritual well-being</i></p> <p>FACIT-Sp: Improved at 6 months, mean difference: 3.98 points (95% CI: 0.46 to 7.50; $p = 0.027$)</p> <p><i>6-month mortality</i></p> <p>NS, 30.7% vs 26.7% (p value not reported)</p> <p><i>HF-related rehospitalization</i></p> <p>NS, 30.7% vs. 29.3% (p value not reported)</p>	Low	Low

*Patient population details the indication for palliative care. All comparisons stated as intervention versus control.

ESCAPE = Evaluation Study of Congestive Heart Failure and Pulmonary Artery Catheterization Effectiveness; FACIT-Pal = Functional Assessment of Chronic Illness Therapy—Palliative Care; FACIT-Sp = Functional Assessment of Chronic Illness Therapy—Spiritual Well-Being; HADS = Hospital Anxiety and Depression Scale; KCCQ = Kansas City Cardiomyopathy Questionnaire; NP = nurse practitioner; other abbreviations as in [Table 1](#).

Table 4. Summary of Existing Trials of Home-Based Specialty Palliative Care in HF. (Kavalieratos et al., 2017)

Study (Ref. #), Year (Country)	Patient Population*	Intervention (Participants Randomized)	Control (Participants Randomized)	Results	Risk of Bias	
					Subjective	Objective
Brännström et al. (51), 2014 (Sweden)	NYHA functional class III-IV HF (mean age: 79 yrs)	Predominately in-home HF disease management and palliative care services via a multidisciplinary approach and care coordination (n = 36)	Usual care (n = 36)	<i>QoL</i> EQ5D: Improved (57.6 ± 19.2 vs. 48.5 ± 24.4 ; $p = 0.05$) KCCQ: NS (data not reported) <i>Symptom burden</i> ESAS: NS (data not reported) 6-month survival NS; $p = 0.34$ <i>Hospitalizations</i> Reduced; 0.42 ± 0.60 vs. 1.47 ± 1.81 ; $p = 0.009$ <i>Total costs</i> NS; mean €4,078 vs. €5,727 (p value not reported) <i>Increased proportion of patients with improved NYHA functional class</i> 39% vs. 9%; $p = 0.015$	High	High
Wong et al. (50), 2016 (Hong Kong)	Advanced HF (e.g., NYHA stage III-IV) (mean age: 78 yrs)	Palliative care home nurses conducted home visits/telephone calls providing transitional palliative care (n = 43)	Usual care (n = 41)	<i>Symptom burden</i> ESAS: Proportion of patients with improvement in total score, 73% vs. 41.4%, $p < 0.05$ <i>QoL</i> McGill: Improved at 4 weeks; 7.57 points vs. 6.46 points; $p < 0.001$ Chronic HF Questionnaire: Improved at 4 weeks; 5.26 points vs. 4.47 points; $p < 0.001$ <i>Satisfaction with care</i> Higher at 4 weeks; 48.84 points vs. 3.55 points, $p < 0.001$ <i>Hospital readmission</i> NS at 4 weeks; 20.9% vs. 29.3%, $p = 0.38$; reduced at 12 weeks: 33.6% vs. 61%, $p = 0.009$	High	High

*Patient population details the indication for palliative care. All comparisons stated as intervention versus control.
EQ5D = EuroQoL Five Dimensions Questionnaire; other abbreviations as in [Tables 1 and 2](#).

Table 5. Summary of Existing Trials of Primary Palliative Care/Collaborative Care Models in HF. (Kavalieratos et al., 2017)

Study (Ref. #), Year (Country)	Patient Population*	Intervention (Participants Randomized)	Control (Participants Randomized)	Results	Risk of Bias	
					Subjective	Objective
Bekelman et al. (52), 2015 (U.S.)	HF with poor QoL, limited functional status, and significant symptoms (KCCQ score <60) (mean age: 68 yrs)	Multidisciplinary collaborative HF disease management, and telemonitoring with patient self-care support (n = 187)	Usual care (n = 197)	<i>QoL</i> KCCQ: NS at 1 yr; 54.2 (95% CI: 51.7 to 56.6) vs. 53.6 (95% CI: 51.1 to 56.0) <i>Mortality</i> Decreased at 1 yr; 4.3% vs. 9.67%, $p = 0.04$ <i>Mood</i> PHQ-9: Improvement in depression among patients with initial positive screen; mean difference: 2.1-point reduction (95% CI: 0.43 to 3.78; $p = 0.01$) <i>Hospital readmission</i> NS at 1 yr; 29.4% vs. 29.9%; $p = 0.87$	Unclear	Unclear

*Patient population details the indication for palliative care. All comparisons stated as intervention versus control.
Abbreviations as in [Tables 1 and 2](#).

