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Palliative Care in the Management of Patients with Advanced Heart Failure

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Abstract

Globally, there are 18-million individuals living with heart failure, a disease that is responsible for 12–15 million office visits and 6.5 million inpatient hospitalizations each year. As HF becomes advanced or end-stage, patients often live in a cycle of frequent transitions between care settings, and with unmet needs, including distress from inadequately managed symptoms. Prognostication in patients with heart failure can be challenging due to the unpredictable exacerbating-remitting illness trajectory that is associated with this progressive disease. Recurrent hospitalizations, worsening functional status and refractory symptoms, despite optimal therapies, are among the most salient predictors indicating that patients with advanced heart failure are nearing the end of life. Palliative care is a specialized form of medical care that has been shown to help improve severity of symptoms, facilitate discussions regarding medical decision making/advance care planning, and provide support for patients and their families. Palliative care can be used alongside curative treatments and has been shown to improve patient satisfaction and quality of life. Anorexia-cachexia syndrome, dyspnea, fatigue, pain and depression are among the most common symptoms experienced by patients suffering from advanced heart failure. Palliative care can help alleviate these symptoms and also facilitate conversations about decision making surrounding resuscitation status and use or deactivation of medical devices, such as an implantable-cardioverter-defibrillator (ICD). Clinical practice guidelines from the American College of Cardiology and American Heart Association report that aggressive life-sustaining treatments and therapies should not be utilized in patients with advanced heart failure who have refractory symptoms that are not responding to medical therapy. The focus of care should switch to controlling symptoms, reducing hospital admissions and improving health-related quality of life, which can be supported by the incorporation of palliative care into the treatment plan.

Keywords

Advanced care planning · Advanced heart failure · End-of-life care · Heart failure · Palliative care · Symptom management

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1 Introduction to Advanced Heart Failure

The heart is one of the most complex organs in the body. It is at the center of the circulatory system pumping oxygen-rich blood to all parts of the body (U.S. Department of Health and Human Services, National Heart Lung and Blood Institute 2011). The performance and health of the heart muscle is vital to ensure survival. Over time, the ability of the heart to adequately pump blood to other parts of the body can weaken. It can affect either the left or right side of the heart or both (U.S. Department of Health and Human Services, National Heart Lung and Blood Institute 2015a). This condition is known as heart failure and it is the progressive outcome from a variety of cardiovascular diseases, such as coronary artery disease, hypertension, arrhythmias and cardiomyopathy (U.S. Department of Health and Human Services, National Heart Lung and Blood Institute 2015b). Congestive heart failure occurs when blood backs up into various organs, such as the lungs and kidneys, due to the inefficiency of the heart to pump. This can affect the function of those organs and can cause significant distress from presenting symptoms. Although not all heart failure is classified as congestive, its effects can contribute to a host of adverse symptoms and stressors on the body of those who are affected (American Heart Association 2017a).

According to the American College of Cardiology/American Heart Association (ACC/AHA), the progression of heart failure is categorized into 4 stages (Hunt et al. 2009). Individuals who have risk factors for heart failure but have no structural heart disease are classified as stage A, whereas patients who have risk factors and the presence of asymptomatic heart disease are classified as stage B. Stage C encompasses the largest percentage of patients and includes patients who have active symptomatic disease. Stage D represents advanced or end-stage heart failure and is characterized by the presence of refractory symptoms despite the implementation of available medical therapies (Hunt et al. 2009). This paper will focus exclusively on the management of patients who present with advanced, or stage D, heart failure and the use of palliative care interventions in their overall treatment plan.

1.1 Prevalence

Heart failure has become an all too common chronic illness affecting nearly 6 million people in the United States and nearly 18 million people globally (World Health Organization 2017a). Heart disease is the leading cause of death worldwide affecting men and women alike, regardless of ethnicity or racial origin. Of the 6 million people who are diagnosed with heart failure, approximately 10% have advanced, or stage D, heart failure (American Heart Association 2017b). Heart failure has no cure and although there are treatments available to manage the disease, it is a progressive disorder that will eventually worsen despite the best medical therapies.

This disease is costly, both in terms of mortality and economics. One in every three deaths in the United States is the result of heart disease, contributing to the deaths of 2240 people each day (American Heart Association 2017c). Heart failure is responsible for 12–15 million office visits and 6.5 million inpatient hospitalizations each year (Hunt et al. 2009). According to the American Heart Association, the estimated cost of cardiovascular disease in 2010 was $863 billion and is expected to rise to $1044 billion by 2030 (American Heart Association 2017c). Patients with heart failure live with many distressing symptoms that can affect their functional status and quality of life (Heo et al. 2014). Heart failure affects older adults more than any other age category, with 80% of patients who are hospitalized with this disease aged 65 years or older. The incidence and prevalence of heart failure will escalate alongside the projected growth of the older adult population expected to reach 83.7 million by the year 2050 (United States Census Bureau 2014).

1.2 Illness Trajectories in Advanced Heart Failure

An illness trajectory is the common course or pattern of progression that is associated with a specific type of illness. The term trajectory is defined as "a path or course", therefore illness trajectory can be defined as "a course of illness" and is the usual pattern or progression of an illness or disease (Merriam-Webster 2017a). It is important to understand which illness trajectory is most commonly associated with heart failure in order to be able to anticipate prognosis and inform the patient and family what to expect. Many patients want to know what will happen to them when they are diagnosed with an illness. This is especially true if the disease is not fully curable and the patient will have to live with the illness for the rest of his/her life.

Illness trajectories were first studied by Glaser and Strauss (Glaser and Strauss 1965) who examined the various illness trajectories that people who were dying often went through. Three trajectory types were classified: surprise deaths, expected deaths, and entry-reentry deaths. Surprise deaths were usually unexpected and occur without any warning, such as a car accident. Expected deaths occur in individuals diagnosed with a known terminal illness in which death was the expected outcome with disease progression. Entry-reentry deaths reflect the trajectory that is most aligned with heart failure and describes a typically slower illness trajectory characterized by intermittent acute exacerbations followed by periods of remission. There is a slower decline associated with this type of trajectory and while patients may recover from an exacerbation, they often do not return to their previous level of functioning, losing a little more function with each subsequent exacerbation.

2 Prognostication in Advanced Heart Failure

The exacerbating-remitting illness trajectory can make prognostication difficult in patients with advanced heart failure, as it is difficult to predict with any certainty when the next exacerbation will occur. Prognostication in heart failure can be challenging because of the unpredictability with the course of the illness and severity of exacerbations. Previous research has examined this topic with much variation in their results. In a sample of 1433 patients with advanced heart failure, the estimated 1-year survival was 71.9% (Costanzo et al. 2008) whereas another similar study found the 6-month survival to be only 67% (Allen et al. 2008). The estimated 1-year survival was found to be 25% in a randomized control trial that compared two cohorts of patients; one undergoing destination ventricular assist device (VAD) therapy compared with a cohort receiving only medical management (Rose et al. 2001). Despite this variation, heart failure research has continued to grow and subsequently findings have supported the most salient clinical indicators to help physicians with accurate prognostication of patients with heart failure.

2.1 Predicting Prognosis in Advanced Heart Failure

Although prognostication can be difficult due to an unpredictable illness trajectory and other factors that may be involved, there are several key components that can assist providers with predicting prognosis for a patient with heart failure. Previous research has shown several indicators that strongly correlate with a limited prognosis in patients with heart failure (Reisfield and Wilson 2007). These include: decreased left ventricular ejection fraction equal or less than 45%, elevated blood-urea nitrogen and/or creatinine 1.4 mg/dl or higher, recent cardiac hospitalization, ventricular dysrhythmias that are resistant to treatment, reduced functional status, anemia, hyponatremia, cachexia, and presence of other co-morbidities (Reisfield and Wilson 2007).

More recent research has supported the use of biomarkers for the diagnosis, treatment, and prognostication in patients with heart failure

(Schmitter et al. 2014). Three well-established biomarkers for heart failure include the brain natriuretic peptide (BNP), N-terminal pro-hormone of brain natriuretic peptide (NT-proBNP), and mid-regional sequence of pro-atrial natriuretic peptide (MR-proANP) (Schmitter et al. 2014). Another recent study found increased levels of pro-atrial natriuretic peptide (MR-proANP) to be associated with 10-year all cause mortality and adverse clinical outcomes in community dwelling patients (Odermatt et al. 2017). Since many patients with advanced heart failure die following a visit to emergency care, Lee and colleagues (Lee et al. 2016) conducted the first phase of their ACUTE study to examine the validity of an emergency heart failure mortality risk tool. This will help physicians to accurately identify level of risk among patients who present to the emergency room with symptoms of acute heart failure (Lee et al. 2016).

2.2 Conversations About Goals of Care

Goals of care are the desired outcomes patients have for their medical care and are based on their values and beliefs (Vermont Ethics Network 2011). Goals of care can change over time as patients' circumstances and stage of illness changes and therefore it is important for providers to ask patients about their individual goals of care periodically throughout the illness trajectory. Understanding the unpredictable nature of this the illness trajectory associated with heart failure can be a useful starting point in helping inform patients about what they might expect as their illness progresses. Previous research has demonstrated the lack of these types of conversations early enough in patients' illness trajectories (Hupcey et al. 2016). Often the conversation about goals for care does not occur until the patient is already in the advanced stage of disease. It is important to understand that patients' care preferences may change from a previous hope for a cure and focus on extending length of life, to a new aim on improving comfort and quality of life. When this shift in care preferences occurs, a conversation about the incorporation of palliative care should be initiated.

It is vitally important for providers to have a good understanding about what palliative care is and what it is not, in order to provide accurate and honest information to the patient and family. Family members may be present and involved in conversations about goals of care and there may be discrepancies between what the patient wants and the wishes of the family. Since this can pose a challenge, several family meetings alongside social work, may need to be held before there is resolution in a clear plan of care moving forward. The initiation of palliative interventions can occur alongside of curative medical therapies, and that is an important point to share with patients and families during goals of care conversations.

3 Palliative Care

3.1 Origins of Palliative Care

Palliative care originates from the term "palliate" and is defined as "to reduce the violence of (a disease) and/or to ease (symptoms) without curing the underlying disease" (Merriam-Webster 2017b).

The World Health Organization defines palliative care to be "an approach to care that improves the quality of life for patients with life-limiting illnesses and their families through the prevention and relief of physical, psychosocial and spiritual suffering" (World Health Organization 2014). Although most end-of-life care programs and hospices utilize the underlying philosophy of palliative care, it in itself has become a specialty of care found in over half of all 100+ bed hospitals in the United States (National Hospice and Palliative Care Organization 2014). This equivocates to a 138% increase since the year 2000. Palliative care programs and services are found in both inpatient and outpatient health care settings.

Although palliative care first began alongside the hospice movement, it is its own specialty of care that is widely used by patients who are diagnosed with serious illnesses. It uses a team-based approach to assess and treat adverse symptoms that accompany serious illnesses (National Hospice and Palliative Care Organization 2014). The goal of palliative care is to mitigate or lessen distressing symptoms that affect patients, which will ultimately benefit their quality of life. In addition to a focus on symptom management, palliative care often bridges the gap between medical care and end-of-life care by initiating difficult conversations surrounding prognosis and goals of care. It helps patients with decision making and care planning. Lastly, palliative care helps to provide emotional support for patients and families who are living with serious life threatening illnesses (National Hospice and Palliative Care Organization 2014).

3.2 Provision of Palliative Care

Palliative care can be incorporated into the care of patients who have been diagnosed with a serious life limiting illness. It can be used by patients of any age or alongside any stage of illness because the overarching goal is to improve quality of life (Center to Advance Palliative Care 2011). There is no pre-determined life expectancy required to be eligible to receive palliative care. This differs from hospice care, which requires patients to have a life expectancy of 6-months or less in order to qualify for its services (Center to Advance Palliative Care 2011). Some healthcare organizations may offer one or more sub-specialties of palliative care focused on a specific population. Geriatric and pediatric palliative care are two examples of sub-specialties that focus on improving the quality of life for older adults and children, respectively. Palliative care is covered by Medicare, Medicaid and most private insurances or HMO’s (Start the Conversation.Org 2017).

In addition to the requirement of a 6-month life expectancy, the other marked difference between palliative care and hospice are the regulations governing curative versus comfort care. Palliative care can be used alongside life-sustaining or curative treatments in patients who are diagnosed with a serious life limiting illness. This differs from hospice care in that hospice requires patients to forgo all curative or life-sustaining medical treatments and elect to receive solely comfort care measures (National Hospice and Palliative Care Organization 2014).

Palliative care might be a better option than hospice for patients who are living with certain chronic illnesses, such as heart failure. This is because some of the regulations that stipulate what is covered or allowable treatments by hospice may not be consistent with patients’ wishes or goals of care. This pertains to patients, such as those with heart failure, who have periodic exacerbations of illness that require inpatient care and the administration of medications that are not routinely covered by hospice because they are considered to be curative in nature. Patients with advanced heart failure may find more benefit with the provision of palliative care interventions alongside their treatment plan rather than electing solely hospice care. This is because many of the interventions routinely used for symptom management are considered curative and would not be reimbursable through the current regulations of the hospice benefit (Lowey et al. 2014).

3.3 Indication for Palliative Care

The benefits of palliative care for patients with heart failure have been recognized by the American Heart Association, American College of Cardiology and the Heart Failure Society of America (Diop et al. 2017). The ideal timing for initiation of palliative care is not well understood despite consensus statements and panels that have advocated for its delivery alongside curative medical care. What we do know is that patients who are diagnosed with ACC/AHA Stage D heart failure and/or patients who develop symptoms classified by the New York Heart Association as Class III or IV, may benefit from palliative interventions (Teuteberg 2016).

Additionally, discussion surrounding palliative care should be initiated with “patients who have more frequent inpatient hospitalizations for heart failure exacerbations, present with refractory angina, have recurrent implantable cardiac device (ICD) shocks, and levels of anxiety or depression that adversely affect quality of life” (Teuteberg 2016). Lastly, early conversations with patients to establish their goals of care and periodic re-visitation of these goals, is an essential component that will enable providers to determine when their patients would most benefit from the incorporation of palliative care into their treatment plan.

4 Management of Symptoms in Advanced Heart Failure

4.1 Anorexia/Cachexia

Anorexia is a common symptom that accompanies many types of advanced illnesses. It is defined as the “reduction or loss of desire to eat” (Wholihan 2015). In acute diseases, anorexia can be corrected or reversed when the illness resolves. In progressive advanced illnesses, such as heart failure, anorexia can be more challenging to manage. If patients are not able to consume enough calories, it will lead to protein-calorie malnutrition and subsequent weight loss (Wholihan 2015). Unresolved anorexia can lead to cachexia, and the presence of both together has been coined anorexia-cachexia syndrome in progressive disease or cardiac cachexia when associated primarily with heart failure (von Haehling et al. 2009). Cardiac cachexia is estimated to arise in 16–36% of patients with advanced heart failure (Wholihan 2015). Cachexia is defined as wasting away from lack of adequate nutritional intake and/or progressive weight loss (Wholihan 2015). Decreased appetite typically accompanies both anorexia and cachexia, however the latter can occur without the presence of a decreased appetite (Wholihan 2015). Wasting of skeletal muscle and fatigue often accompany anorexia-cachexia syndrome (Wholihan 2015) which may be difficult to treat in patients who are nearing the end of life.

Early signs of anorexia-cachexia syndrome include: reduced appetite, alterations in taste, and early satiety (Wholihan 2015). These signs can lead to weight loss, wasting of muscle and adipose tissue, fatigue and decreased functional status (Wholihan 2015). Decreased food intake will lead to metabolic alterations, decreased immune response and systemic inflammation (Wholihan 2015) which can develop into a devastating cycle and progressive worsening of patients’ underlying condition. In addition to its physiological effects, anorexia-cachexia syndrome contributes to psychological and spiritual distress for the patient and family. It can have profound effects on quality of life. Assessment should include a thorough nutritional intake and appetite evaluation. There are several validated tools available to assess nutritional status including the Subjective Global Assessment for Nutrition (Wholihan 2015), which focuses exclusively on nutrition or the Memorial Symptom Assessment Scale (Wholihan 2015), which focuses on several symptoms including appetite.

Palliative management of patients with anorexia-cachexia syndrome should be focused on reducing the distress caused by anorexia and subsequent weight loss in an effort to improve comfort and quality of life. Non-pharmacological interventions include: encouraging small meals served at room temperature, initiating more heavily caloric or nutritional foods/liquids first in the meal, avoiding foods and liquids with little or no nutritional value, introducing over-the-counter nutritional supplements, and supporting patients and families to continue to offer cultural dishes and maintain family mealtime rituals (Wholihan 2015). Pharmacological interventions include megestrol acetate, which has shown to stimulate appetite and promote weight gain. The majority of these studies were in cancer patients, and therefore the benefit in non-cancer illnesses such as heart failure, are not well known (Wholihan 2015). Some studies have found a positive correlation between fluid retention and megestrol use, however, larger multisite studies are needed to provide stronger validation of this side effect in heart failure patients (von Haehling et al. 2009).

The use of artificial nutrition and hydration is a common topic that arises during conversations about management of anorexia and cachexia. Although administering nutrition and fluids through artificial means might have good benefits for patients with an acute trauma or illness, the benefits for patients with advanced or terminal illnesses are less known. We do know that the use of artificial nutrition and hydration can contribute to several unwanted complications among patients with advanced disease. This includes: nausea and vomiting, loose stools, aspiration, shortness of breath, edema and dumping syndrome (End of Life Nursing Education Consortium (ELNEC) n.d.). Patients who are nearing or at the end of life may have little to no benefit from artificial feedings and have been found to contribute to increased discomfort and further reduction in quality of life (End of Life Nursing Education Consortium (ELNEC) n.d.). Providers should evaluate the patient's goals of care in conjunction with stage of illness before deciding whether artificial nutrition or hydration should be initiated.

4.2 Confusion

It is not atypical for patients with heart failure to present with cognitive impairments, confusion or delirium. This has been found to be related to decreased cardiac output and reduced cerebral blood flow (Whellen et al. 2014). These cognitive deficits can be compounded by the age of most heart failure patients, as normal age related changes may also be present. Patients may be subject to higher rates of hospitalization, greater functional deficits and increased mortality (Heidrich and English 2015). Certain medications, such as benzodiazapines, opioids and even some cardiac medications, such as beta blockers and ACE inhibitors, can further contribute to confusion and delirium. Among hospitalized patients, delirium has been reported in 14–56% of patients and up to 80% of patients who were mechanically ventilated in ICU's (Heidrich and English 2015).

The Confusion Assessment Method (CAM) and Memorial Delirium Assessment Scale (MDAS) are two clinical instruments that can easily be used to evaluate patients' cognition in the clinical setting (Heidrich and English 2015). In patients who are not actively dying, palliative management includes removing the source that is contributing to confusion or delirium, such as reducing medication dosages or treating underlying medical conditions, such as an infection. Terminal restlessness is a term used to describe increased agitation, confusion and restlessness experienced by some patients as they near the end of life (Heidrich and English 2015). If the patient is exhibiting other signs that indicate their condition is rapidly progressing and they are actively dying, palliative management would focus on reducing the distress associated with the symptom/behavior and ensuring the safety of the patient and those around him/her. Antipsychotic medications, particularly haloperidol, is the medication of choice for management of terminal restlessness or agitation (Heidrich and English 2015). This medication typically has fewer side effects than anticholinergics or benzodiazepine medications, and can be given in a variety of routes. Lorazepam should ideally not be used because it has been demonstrated to worsen delirium in older adults (Heidrich and English 2015).

4.3 Cough

Cough can be a common occurrence in patients with heart failure. Cough can be dry or productive, depending on the origin. Patients with heart failure can develop a cough due to pulmonary congestion, the presence of an underlying infection or result from the use of an ACE inhibitor used to manage their heart condition (Whellen et al. 2014). Cough is often worse at night, when the patient is lying down. Frequent coughing can lead to irritation in the respiratory tract and trachea, pain, nausea from retching, and even fractured ribs (Dudgeon 2015). It can contribute to poor sleep, nutrition and increased fatigue, which can greatly decrease the patient's quality of life.

Management for cough begins by evaluating the underlying cause or source of the cough. This includes ruling out any underlying infection or escalating exacerbation. For patients whose cough is caused by ACE inhibitor, an angiotensin receptor blocker (ARB) can be substituted (Katz and Konstam 2009). Palliative treatment for a non-productive cough can include: antitussive medications, such as dextromethorphan, opioids, and inhaled anesthetics for severe cases (Dudgeon 2015). Treatment for a productive cough can include: expectorants, mucolytics, antihistimines, and anticholinergics to decrease sputum production. Oxygen and chest physiotherapy may also be used (Dudgeon 2015).

4.4 Dyspnea

Dyspnea, also referred to as shortness of breath or breathlessness, is a common and distressing symptom experienced by patients with advanced heart failure. A recent systematic review found that 60–88% of patients with cardiac disease experience some type of dyspnea (Solano et al. 2006). Breathlessness has been described by patients as a profound heaviness or weight sitting on their chest and the inability to take in enough air to breathe (Lowey et al. 2013). This can be a frightening experience and has been associated with increased levels of anxiety and depression (Lowey et al. 2013). The cause of dyspnea is often multidimensional and its treatment can be difficult in patients with advanced heart failure. Dyspnea may become refractory in advanced or end-stage heart failure, which means that the underlying cause cannot be reversed and the focus of care should shift to interventions aimed at palliation (Abernathy et al. 2003).

In palliative care, the gold standard management for refractory dyspnea in end-of-life care is the use of an opioid medication (Lanken et al. 2008). Caution should be taken when prescribing an opioid medication to patients with heart failure, because their increased age and presence of other co-morbidities can contribute to the build-up of toxic metabolites (Dudgeon 2015). Benzodiadapines have also been shown to help reduce anxiety that is associated with breathlessness. The benefits associated with administering opioids and benzodiazapines for patients who are nearing the end of life or actively dying, may outweigh the risks, since the focus of palliative care is on maximizing comfort and improving quality of life (End of Life Nursing Education Consortium (ELNEC) n.d.).

Some non-pharmacological interventions may help alleviate the sensation of breathlessness in patients with advanced heart failure. Several systematic review articles on this topic found that interventions that promote muscle strengthening, such as cardiac rehabilitation and respiratory muscle training, have produced the most positive results in clinical trials (Buckholz and von Gunten 2009; Bausewein et al. 2008). Activities that promote energy conservation, such as the use of walking aids, have also been found to help reduce dyspnea. Although the literature lacks strong evidence that supports the benefit for complementary therapies, such as acupuncture, some of these therapies have shown promise (Buckholz and von Gunten 2009). Lastly, since the presence of anxiety is strongly associated with the dyspnea experience, interventions that support emotional and cognitive factors can be beneficial. This includes counseling, psychotherapy, and relaxation techniques. Eliciting changes in the patient's environment, such as ensuring enough surrounding open space and keeping the air well circulated through the use of a fan and/or open window, have been reported to promote comfort with breathing by patients (Dudgeon 2015). More large multi-site controlled trials that examine the benefits of these and other non-pharmacological therapies are needed.

4.5 Edema

Fluid overload associated with poor cardiac output and issues with perfusion can contribute to the development of edema and/or ascites in patients with advanced heart failure (Whellen et al. 2014). This can be very uncomfortable and contribute to or worsen other symptoms, such as pain and shortness of breath (Adler 2009). Edema is especially prevalent in right-sided heart failure, which causes a buildup of blood behind the heart which precipitates increased systemic venous pressure (Katz and Konstam 2009). The presence of excess fluid in soft tissues causes swelling, which can be classified as pitting or non-pitting edema. "Cardiac edema" is edema that is most pronounced in the lower extremities in patients with right-sided failure (Katz and Konstam 2009). Chronic edema caused by an underlying illness can develop into lymphedema (Fu and Lasinski 2015).

Treatment for edema involves the administration of diuretic medications, elevation of the affected extremity and compression stockings (Adler 2009). Medications and foods that contribute to increasing levels of sodium and/or fluids should be avoided (Whellen et al. 2014). Evaluation of daily weights with subsequent titration of diuretic medications should also be part of the treatment plan.

4.6 Fatigue

Fatigue is one of the most common and chronic symptoms associated with many serious diseases. Research that has examined symptom clusters, which are described as "concurrent and related symptoms that may or may not have a common etiology" has found the presence of fatigue in 7 out of the 9 studies that were evaluated (Bookbinder and McHugh 2010). It is a common and prevalent symptom that is associated with heart disease, chronic obstructive pulmonary disease, cancer, renal disease, HIV/AIDS and multiple sclerosis (O'Neil-Page et al. 2015).

Two theoretical models have been reported in the literature that offers an explanation for the underlying pathophysiology of fatigue: the accumulation and depletion hypotheses. The accumulation hypothesis suggests that fatigue is caused by the body's inability to dispose of waste products that have accumulated in the body. Whereas the depletion hypothesis suggests the opposite; that the lack of certain substances that are vital for the body to function, are reduced or missing (O'Neil-Page et al. 2015). The presence of other co-morbidities, such as anemia, dehydration, cachexia, electrolyte imbalance, thyroid dysfunction and infection have also been identified as contributing factors associated with the development of fatigue (Adler 2009).

Palliative management of fatigue can be complex due to the multi-factorial components that may be involved. The first step is a thorough evaluation of fatigue severity, onset, duration, usual pattern or presentation, alleviating and exacerbating factors, and impact on functional abilities and quality of life (Yennurajalingam and Bruera 2007). There are several validated scales available to assist with the evaluation and diagnosis of fatigue including: the Multidimensional Fatigue Inventory, Multidimensional Fatigue Symptom Inventory, and the Edmonton Symptom Assessment Scale (Yennurajalingam and Bruera 2007). In palliative care, if reversal or discovery of the underlying condition causing fatigue is not possible, management should be aimed at treating the associated and distressing symptoms. This can include the management of pain, depression, delirium, and anorexia (Yennurajalingam and Bruera 2007).

Pharmacological management of fatigue includes the administration of corticosteroids, methylphenidate, or modafinil (O'Neil-Page et al. 2015; Yennurajalingam and Bruera 2007). Research has also found some benefit with the addition of megestrol, normally used to promote appetite, also improves fatigue and sense of well-ness (Yennurajalingam and Bruera 2007). Non-pharmacological management includes the use of energy conservation, which was identified as the most frequently utilized treatment for fatigue (Yennurajalingam and Bruera 2007). Resistance training and exercise were also noted to have benefits (Yennurajalingam and Bruera 2007).

4.7 Insomnia

Insomnia and problems related to sleep are common among patients with advanced heart failure and are most often related to the presence of orthopnea or paroxysmal nocturnal dyspnea. Previous research found the prevalence of insomnia among patients with cardiac disease to be as high as 44% (Evangelista et al. 2009) with 50% of patients diagnosed with sleep disordered breathing, such as obstructive sleep apnea (Whellen et al. 2014). The primary treatment for patients with sleep disordered breathing is continuous positive airway pressure (CPAP). This therapy, however, may not be well tolerated by patients in advanced stages of the disease.

Palliative management of insomnia includes trying to remediate the underlying cause, if possible, and then focusing on alleviating any adverse effects. Pharmacological management could include medications used for anxiety/depression, such as benzodiazapines, if those symptoms are found to result from sleep deprivation. Low dose zolpidem can also be trialed for patients whose symptoms are affecting quality of life (Whellen et al. 2014). Providers should educate patients to be wary of side effects from these medications, particularly in older adults. Patients should be encouraged to maintain bedtime routines and to minimize noise and external lighting at bedtime. The room temperature should be tailored to individual patient preferences.

4.8 Pain

Patients with heart failure can be subject to experience various types of pain. Some pain can be related to their cardiac health, such as chest pain associated with angina, while others may be related to osteoarthritis or peripheral vascular disease. One study found 89% of end-stage heart failure patients have pain (Evangelista et al. 2009). Pain is classified by its etiology (somatic, visceral, or neuropathic) and also by pattern of presentation, which can be acute or chronic. (Coyle and Layman-Goldstein 2001).

Patients with heart failure should be asked about their current location of pain, duration, intensity, quality, aggravating and alleviating factors and current pain management regimen (End of Life Nursing Education Consortium (ELNEC) n.d.). Once the origin of pain is determined, the provider can determine the most optimal pain management plan for the patient. It is ideal to include both pharmacological and non-pharmacological interventions in the pain management plan. In palliative care, pain that is acute and determined to resolve in a short period of time is treated using a short-acting analgesic whereas pain that is chronic should include the use of both a long-acting and short-acting analgesic medication (End of Life Nursing Education Consortium (ELNEC) n.d.). Since the majority of patients with advanced heart failure are older adults, pain medications should be used according to the World Health Organization (WHO) three-step ladder for pain in adults (World Health Organization 2017b). The aim of pain management is to treat pain with the lowest type of analgesia that will mitigate the pain and limit unwanted side effects.

Opioid medications are the most widely used pharmacological treatment for patients who have moderate to severe pain (Adler 2009). Combination medications and non-steroidal inflammatory medications should be avoided in older adult patients, such as those with heart failure (Adler 2009). Although providers should use caution when prescribing narcotic medications, particularly in older adults because it may contribute to falls, delirium, and urinary retention (Eliopoulos 2014), the focus of palliative care is to improve quality of life, and the benefits for reducing symptoms should be weighed against any minimal risks.

4.9 Anxiety & Depression

The chronic and progressive nature of advanced heart failure includes periods of exacerbations when the disease worsens. The unpredictable nature of exacerbations can contribute to feelings of anxiety and depression among patients. Depression has been found to be present in 21–36% of patients with heart failure and with even greater prevalence among patients who have advanced disease (Adler 2009). The presence of depression and anxiety have been shown to correlate with greater symptom burden and more frequent hospitalizations (Goodlin 2009) and patients who report depression have greater fatigue and other symptoms than patients without depression.

The evidence suggests that many of the traditional medications used to treat depression can contribute to adverse effects in patients with heart failure. Selective serotonin reuptake inhibitors (SSRI's) can place patients at risk for fluid retention and/or hyponatremia and these medications can also take several weeks to be fully titrated (Goodlin 2009). Tricyclic antidepressants are another class of medications that can be used instead of SSRIs. They have however, been found to contribute to prolonged QT intervals at higher doses and also have a 1–2 week lead time for full titration to occur (Goodlin 2009). To date, the best evidence suggests the use of methylphenidate due to its minimal adverse effects with this patient population (Goodlin 2009). Benefit from this and/or other psycho-stimulant medications can be seen in 1–2 days rather than weeks, as with the before mentioned classes of medications. Benzodiazapines have also been found to be effective in reducing anxiety among patients with heart failure at any stage of the disease (Goodlin 2009).

Non-pharmacological interventions for depression and anxiety include measures aimed at providing emotional support, such as support groups and mindfulness education programs (Sullivan et al. 2009). These interventions promote patients to increase their sense of control related to heart failure symptoms, which can subsequently reduce feelings of anxiety and depression (Sullivan et al. 2009).

5 Quality of Life and Functional Status

Patients with advanced heart failure can experience a wide range of adverse and uncomfortable symptoms that accompany disease progression. This can significantly impact the quality of daily life and contribute to physiological, psychological and spiritual distress. Worsening of the heart also leads to functional limitations and disability which can both have a profound effect on patients and their caregivers. Limitations can include all of the activities of daily living (ADLs). There are six basic ADLs which are: bathing, dressing, eating, toileting, transferring (ambulating) and continence (Eliopoulos 2014). The symptoms associated with heart failure can impact any or all of the patient's ability to complete their ADLs. This can then contribute to other issues and concerns, which in turn can worsen the patient's overall health and well being. Additionally, loss of these functional abilities not only impact the patient, but their family members, many of whom may be the assisting the patient by providing informal care.

The loss of a patient's functional ability and subsequent loss of independence in being able to carry out the activities of daily living, are both losses that can contribute to feelings of grief. Grief is a universal experience that individuals go through when dealing with a loss. Although losses are often defined in terms of a loss of a family member or friend, non-human types of losses, such as loss of independence, can also precipitate feelings of grief (End of Life Nursing Education Consortium (ELNEC) n.d.).

5.1 Caregiver Support

There has been a multitude of research aimed at understanding the caregiver experience and interventions aimed at providing better support for this population. The burden associated with caregiving can impact both physical and mental health of caregivers, which can ultimately impact the care of the patient (Pressler et al. 2013). Caregivers may also experience a financial impact as a result of the time devoted to caregiving (Pressler et al. 2013). Caregivers for patients with heart failure have been found to experience increased levels of depression and anxiety and report decreased quality of life (Pressler et al. 2013).

Early intervention and assistance to the caregiver is vital because of the extended length of time that most caregivers will be providing care to their loved ones with heart failure. McMillan and colleagues conducted an intervention for the caregivers of hospice patients with advanced heart failure and found caregivers have greater benefit with early intervention rather than when their loved one was in the later stages of disease (McMillan et al. 2013).

6 Ethical Challenges

Patients who live with serious and progressive illnesses are often faced with making medical decisions as their illness worsens and they near the end of life. Some of these decisions involve a determination of what the patient wishes or wants done for them medically in the event they are no longer able to make decisions. As difficult as it is to engage in advance care planning, it is most ideal for the patient to make these decisions known before they become incapacitated (Martinez-Selles et al. 2017). This future care planning should ideally include discussion about patient preferences for resuscitation status, withholding and/or withdrawing care, artificial nutrition/hydration and use/discontinuation of device therapy (Martinez-Selles et al. 2017).

6.1 Resuscitation Status and Advance Directives

An advance directive is a legal document that states the types of medical care a patient wants in the event that they are no longer able to make their own decisions (Patients Rights Council 2013). Instituting a living will, identifying a health care proxy and designating a durable power of attorney for health care are three of the most common activities that can be done with advance care planning. These documents or designations enable the patient to identify their wishes for medical care beforehand and/or identify an individual to make those medical decisions on behalf of the patient (Patients Rights Council 2013).

Do Not Resuscitate (DNR)/Do-Not-Attempt Resuscitation (DNAR) In previous years, the acronym (DNR) was used for do-not-resuscitate, which meant that a patient elected to forgo medical intervention if they went into cardiopulmonary arrest (Breault 2011). Another acronym (DNAR), do-not-attempt resuscitation, has recently been added by the American Heart Association (Breault 2011). This is viewed as a less "harsh" term used for the decision to not intervene medically in the event a patient goes into cardiac arrest. If a patient has elected their resuscitation status to be DNR/DNAR, they have decided against initiation of cardiopulmonary resuscitation if they go into cardiac arrest. This includes the use of chest compressions, administration of cardiac medications and the placement of a respiratory/breathing tube (Breault 2011).

The majority of patients with advanced heart failure are older adults. Advanced age was found to be a factor associated with having poor outcomes with use of CPR (Berry and Griffie 2015). CPR was found to only be successful in about 18% of hospitalized patients (Berry and Griffie 2015) with an even lower success rate among patients with advanced illnesses, such as cancer or end stage heart failure.

Allow Natural Death (AND) Allow natural death is a term being used in some health care institutions in place of the traditional DNR/DNAR terminology. Patients who have an AND order want only comfort measures taken for symptom management as they go through the dying process (End of Life Nursing Education Consortium (ELNEC) n.d.). The goal of AND is to ensure that the patient is as comfortable as possible while allowing the natural process of dying to progress (End of Life Nursing Education Consortium (ELNEC) n.d.).

6.2 Withholding and Withdrawing Care

Withholding and/or withdrawing care is a controversial topic that has been debated in the literature (Manalo 2013). Both relate to the use of medical interventions at the end of life and can range from minor, such as the use of a non-life sustaining medication, to more complex, such as mechanical ventilation. Withholding medical care means that a medical treatment or intervention available is not initiated whereas withdrawing medical care denotes the cessation or removal of existing treatments that are already being used (End of Life Nursing Education Consortium (ELNEC) n.d.). The rationale behind withholding or withdrawing medical interventions is based on an evaluation of the benefits and burdens for the patient associated with the treatment. Sometimes treatments are determined to be futile in which patients do not receive any beneficial outcome from the intervention (Martinez-Selles et al. 2017). Some life-sustaining treatments could even worsen patients' suffering and decrease their quality of life.

Educating patients with advanced heart failure about illness progression and what they might expect is essential so that patients can identify goals of care. Any interventions used for the patient are solely for comfort or palliative care. This reinforces the importance of patients having an advance directive in place because this can help to decrease the initiation and use of futile medical care from the outset (End of Life Nursing Education Consortium (ELNEC) n.d.).

6.3 Artificial Nutrition and Hydration

Artificial nutrition or hydration (ANH) is defined as a medical intervention that delivers nutrition and/or hydration through artificial means. This involves administering food or fluids through a non-oral route, such as subcutaneously or intravenously (Arenella n.d.). According to the American Hospice Foundation, ANH should not be considered more than basic care rather than as a medical treatment (Arenella n.d.). Previous research suggests that dying patients derive some benefit from not being able to eat or drink. It has been found to reduce nausea and subsequent vomiting, shortness of breath and edema (Brody et al. 2011), some of which are common symptoms found among patients with advanced heart failure.

6.4 End of Life Decisions Regarding Device Therapy

An implantable-cardioverter-defibrillator (ICD) is a medical device utilized in patients at risk for sudden cardiac death with known ventricular tachycardia or fibrillation (American Heart Association n.d.). ICDs help to prevent cardiac arrest in patients at risk for ventricular arrhythmias and newer models can also dually serve as a pacemaker device (American Heart Association n.d.). Providers should discuss the benefits and risks associated with this device in patients who may be viable candidates for this option. Patients who already have an ICD whose illness has progressed and who are at the end of life should re-evaluate the usage of this device. The ICD should be deactivated in patients who are actively dying in order to avoid the receipt of multiple shocks which can contribute to great suffering and significant distress at the end of life (Martinez-Selles et al. 2017). The deactivation of the ICD will not hasten death and patients should be informed that resynchronisation therapy will continue even in the absence of defibrillation. Conversations surrounding the discontinuation of an ICD device can be distressing and patients and families should be well supported during these difficult decisions. Management of symptoms using palliative care is especially important to be included in the treatment plan for patients who elect ICD deactivation (Martinez-Selles et al. 2017).

6.5 Active Death Help/Physician-Assisted Suicide

Active death help or physician assisted suicide is common terminology used to describe the purposeful ending of one's life (American Academy of Hospice and Palliative Medicine n.d.). A patient living with a terminal illness may request a prescription from a physician to obtain a lethal dose of medication which the patient will self-administer to end his/her life (American Academy of Hospice and Palliative Medicine n.d.). This differs from palliative care because its goal is to improve overall quality of life, through symptom management and relief of suffering without the intentional hastening of death (American Academy of Hospice and Palliative Medicine n.d.). Most professional associations governing medical providers in the realm of end of life care take a neutral or antagonistic position towards active death help (American Academy of Hospice and Palliative Medicine n.d.).

7 Clinical Practice Guidelines

According to the American College of Cardiology (ACC)/American Heart Association (AHA) Guidelines (Yancy et al. 2017; Yancy et al. 2013), aggressive life-sustaining treatments and therapies should not be utilized in patients with advanced or end-stage heart failure who have refractory symptoms that are not responding to medical therapy. Patients who are in their last months of life should not receive treatments that do not contribute to their recovery or improve their quality of life. This includes intubation, the use of mechanical ventilation, and implantation of a cardiac defibrillator (Yancy et al. 2013). The focus of therapy for patients with stage D disease is to: control symptoms, reduce hospital admissions, improve health-related quality of life, and to establish end of life goals (Yancy et al. 2013). It is during this stage that the incorporation of palliative care or hospice should be initiated and the deactivation of ICDs should be instituted.

8 Conclusion

Palliative care should be incorporated into the management plan for patients with advanced heart failure. It has been demonstrated to help reduce severity of symptoms, encourage advance care planning and identification of goals of care and reduce patient and family distress affecting quality of life. Understanding the common illness trajectory for patients with heart failure can help providers inform patients about what to expect with illness progression. Palliative care can be initially be instituted alongside curative treatments, and its focus in the overall plan of care can increase as the patient's condition worsens and curative treatments offer less of a benefit. Clinical practice guidelines support the provision of palliative care as an option for the management of patients with ends-stage heart failure.

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