

The Benefits of Palliative Care Interventions for Patients with Heart Failure - A Literature Review

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Abstract

Palliative care is an underused resource with the heart failure patient population. Many of these patients suffer not only from physical ailments but mental, spiritual and financial ones. Heart failure patients face many challenges such as frequent readmissions and a declining quality of life. This not only affects the patients but their families as well. Early palliative care intervention can decrease hospital readmissions and improve quality of life. Although advances in medicine have allowed for the heart failure patient to have more options in prolonging their life, sudden cardiac death may still occur. This uncertainty with the trajectory of death makes it difficult for some health care providers to initiate early discussions of palliative care. Many heart failure patients and their families see heart failure as a benign disease which makes it seem unnecessary for early palliative care interventions. Palliative care, by some people, is perceived as imminent death and not as an improvement to the quality of life. These patients are not being offered appropriate palliative care until their disease has exhausted all treatment plans. Many medical providers do not feel comfortable discussing early palliative care interventions, which in turn can lead to the lack of initiation into the patient's heart failure treatment. Implementing a multidisciplinary team approach will allow cardiologists to work with other health care team members to provide for the highest quality of life. The purpose of this paper is to review the implementation process and benefits palliative care services offered to the heart failure patient community.

Keywords: Palliative care; Heart failure; Cardiology; Primary care

Introduction

In 2002, The World Health Organization (WHO) stated that palliative care should be initiated in an early phase of the disease process. Palliative care is often only offered to patients in the terminal phase of their disease to provide relief of physical symptoms. Heart failure limits the length of lives and profoundly impacts the quality of a patient's life. Patients with advanced heart failure face a variable course with the illness which includes high risk of sudden cardiac death, recurrent exacerbation symptoms and limited knowledge determining the course of the disease. The wide range of symptoms associated with heart failure can be progressive and vary throughout the illness course [1].

Palliative care continues to be on the back burner when it comes to heart failure patients compared to advanced cancer patients. Palliative care has proven to improve symptoms and quality of life with advancing disease or at end of life [2]. Slowly palliative care is being introduced as part of the treatment plan for heart failure patients. Current guidelines set forth by The American College of Cardiology Foundation/American Heart Association Guidelines for the Management of Heart Failure recommend palliative care treatment at the end of life, Stage D heart Failure. Stage D heart Failure can be described as the presence of progressive and/or severe signs and symptoms of heart failure despite medical, surgical and device therapies. Patients generally identified in Stage D heart Failure have limited treatment modalities, morbidity is progressive and survival is decreased [3].

A diagnosis of heart failure can leave a patient and their family struggling to cope with the disease alone and without resources, until they reach Stage D, if the current guidelines are followed. Quality of life decreases as heart failure progresses putting physical and emotional strains on the patient and their caregiver. Depression is one of the psychosocial issues that is prevalent in heart Failure patients that increases as their disease progresses. It is shown that patients with a NYHA Class I heart failure has an 11% depression rate while patients with NYHA Class IV has a 42% depression rate. This increase leads to a decrease in medical compliance, increase in health care visits, decline in health status and an increase in mortality [3]. Heart failure places many burdens on the patients and their care givers which increases the need for palliative care interventions earlier in the diagnosis.

This paper will explore studies introducing palliative care treatments early in the heart failure diagnosis. As medicine today advances and the age of the heart failure patients increases, introducing palliative care early in the diagnosis will allow patients to maintain a higher quality of life with the help of diet, fluid restriction and pain management. Physical quality of life is not the only thing affected by the debilitating heart failure disease, a patient's psychosocial life also decompensates [4].

Discussion

A study by Dartmouth College research team explored the integration of palliative care and patients with heart failure and was consisted of physicians and nurses who developed the program ENABLE (Educate, Nature, Advise, Before Life Ends). This study was introduced to rural, elderly patients suffering with heart failure. It was introduced in two phases by the research team. The ENABLE concept

was expanded from the oncology model. They realized there was a need for a nurse based community resource for caregivers and heart failure patients. The criteria for this study were rural dwelling elderly patients with NYHA class III-IV heart failure. The American Heart Association describes Class III as patients who have marked limitations in physical activity and are comfortable at rest. Less than ordinary activity causes fatigue, palpitations or shortness of breath. Class IV is defined as unable to carry on any activity without discomfort and the discomfort increases with any physical activity, which leads to rise in symptoms of heart failure at rest (American Heart Association (AHA) 2016).

The first phase took place over 4 months, where the team adapted the Chart Your Course guide books from oncology specific to incorporate heart failure topics. The team also interviewed 15 clinicians with background either in cardiology or primary care. The clinicians participated in web based or in person sessions to discuss their views of palliative care, approach of heart failure patients using palliative care treatments, various stages of heart failure and referral triggers for palliative care. The physician group was asked to provide feedback of the design, materials and outcome measures of this intervention. Clinicians expressed difficulty predicting a prognosis for heart failure patients. Many of the clinicians had difficulty initiating a palliative care conversation, as many of their patients do not believe heart failure will kill them. Some patients readily accepted the conversation of palliative care while others were angry at the suggestion. Primary care clinicians in the study believe that they and their colleagues did not have the necessary communication skills to speak to their patients on the topic of palliative care. Some clinicians felt the term palliative care is synonymous with hospice and end of life. Clinicians felt as though there were triggers their patients had that would warrant a palliative care referral but felt they needed a second opinion. The second clinician's evaluation would help to assist with the management of symptoms and development of the disease. During this phase the cardiologists were not opposed to introducing palliative care to their patients at an early stage but had difficulty developing a time frame of the disease. They discussed the difficulty of introducing palliative care and advanced therapies while discussing treatment options. A positive that came from all the clinicians in this phase was involving the same palliative care team from the beginning rather than transitioning the patient to a whole new team when hospice care is needed. They felt continuity was a key for the patients and families [5].

Phase II was introduced over seven months and in total recruited 11 patients and family members/caregivers. All patients with heart failure during this phase of the program were referred to a clinician at Dartmouth-Hitchcock Medical Center where they were screened by the project lead coordinator. The eligible patients met criteria set forth by the committee to continue in this phase. During phase II, the patients provided overall positive feedback. There were 11 heart failure patients and 11 caregivers that participated in this phase. All the patient participants felt that early initiation of palliative care was necessary. A common theme with caregivers was burn out. They expressed they were familiar with many of the coping skills introduced in their sessions during phase II. Introduction of a nurse coach in this phase to the patients helped them change their outlook on life as the disease progressed [5].

As the clinicians expressed, it is difficult to predict the life expectancy of an end stage heart failure patient, this study encountered 2 patients who experienced unexpected deaths within the first 2 weeks of the study and another died after completing the phase II sessions.

This was a 30% sudden death rate for the study. After obtaining the death rate results, the next study will re-evaluate the criteria to include introducing ENABLE earlier in the diagnosis. The study results from phase I and phase II were determined to be effective in the Palliative Care treatment of the heart failure populations. The research team submitted for funding from the National Palliative Research Center to test with a larger sample of participants [5].

In 2015 a study in Netherlands explored training with general practitioners regarding early palliative care needs of their patients. This study had a control group which had no coaching or palliative care team interactions. The other group had palliative care interactions and guidance from a palliative care research team member. Early identification of patients who can benefit from palliative care in conjunction with or as a replacement of a higher level of therapies proved to be a challenge with heart failure patients. This was mainly due to the uncertainty of their life expectancy. This was also a concern voiced by the physicians in the previously reviewed study. There are indicator tools used in the anticipation of the need for palliative care. The Supportive and Palliative Care Indicators Tools (SPICT) is used in Scotland. The Prognostic Indicator Guide (PIG) is used in England. The Radbound indicators for Palliative Care Need (RADPAC) are used by physicians in the Netherlands where this study is taking place.

These tools contain general or disease specific indicators of decline. Some of the areas that are examined are number of hospital admissions, weight loss, decrease in functional status and a question such as; would you be surprised if this patient were to die in the next twelve months [6]? In the Netherlands study, the patients continued to visit their general practitioner who followed their care. The reason why general practitioners were chosen to be part of this study was because of their in depth knowledge of their patients. These practitioners not only are aware of their health conditions but their social/economic status. Continuity of care was a main concern when choosing the physicians for the study. The general practitioner is able to initiate early and timely palliative care interventions for their heart failure patients.

A goal of this study is to have patients visit their general practitioner more which in turn will decrease their hospital admissions and improve the care of these patients. Having the patients die at home and comfortable would be a positive outcome of this study [6].

The control group physicians treated their patients without incorporating new interventions. The intervention group clinicians trained with a palliative care team member and incorporated the RADPAC scoring tool into their practice. They used this on all patients who would potentially benefit from palliative care. After training 57 general practitioners, 28 practitioners identified 52 patients. 29 general practitioners in the intervention group did not identify any suitable patients for this study from their RADPAC results. Some found difficulty with initiating the topic of palliative care or the sudden deterioration of the disease process. A retrospective review of 622 deceased patient charts showed that 487 patients died of either cancer, COPD (Chronic Obstructive Pulmonary Disease) or heart failure where a palliative care intervention could have been initiated. There were no differences in the control group or intervention group in the amount of times a patient sought care for their disease within their last 1-3 months of life. Patients with cancers died often at home while patients with COPD or heart failure died in a hospital setting. This study was considered a weak study, mainly due to the small amount of identifiable patients. The physicians who participated would have benefited with more time to train. Many general practitioners had high

patient load, worked full time or were too busy to attend extensive training [6].

According to the American College of Cardiology and American Heart Association Guidelines for the Management of Heart Failure they recommend palliative care in the later stages of heart failure or with end of life care. A study based at The University of Colorado explored the unmet palliative care needs of the heart failure patient. This study evaluated the lack of palliative care interventions for patients with heart failure by in depth, semi structured, one on one interviews. Caregivers were interviewed separately. The study took place from 2007-2008. Responses were collected from heart failure patients and their caregivers. The responses will be used to design a palliative care plan, addressing concern during the interviews. Study sample patients were obtained using purposive sampling. The age and health status patients varied. Eligible patients were NYHA functional class II-IV. Patients were identified by the University of Colorado Hospital staff using medical record reviews. For the study, 38 patients were identified, 3 refused to participate due to lack of interest and 2 patients felt they were too ill to participate.

Each patient who participated identified their main caregiver, if applicable. The identified caregivers readily responded to the interview process. During the interviews, the team did not use the word palliative during their questioning. They did not want the patient to view their needs in that way. An open ended approach about issue related to advanced health care planning, such as death and dying, were asked when referencing the future. 33 patients and 20 caregivers in total were interviewed. Patients completed a Kansas City Cardiomyopathy Questionnaire (KCCQ) which is a self-reported measurement of heart failure related health status. The KCCQ is a 23 item questionnaire that quantifies physical limitations, symptoms, self-efficacy, social limitations and quality of life [7].

The primary goal of this study was to identify palliative care needs that were not met, concerns and preferences will be used to develop the patient/care giver palliative care intervention for the outpatient setting. The results were further broken down into responses from younger vs elderly patient and NYHA Class II vs NYHA Class III/IV. Once all data was compiled there were key themes noted. These were used to help develop a palliative care intervention for heart failure patients. Some of the common themes compiled were to help patients adjust to the new limitations and future limitations brought on by the disease. They expressed a need for help with adjusting to daily living with a heart failure diagnosis. Supportive assistance with disease progression would be appreciated by both the caregiver and the patient. Some patients sought psychosocial care from mental health professionals and would appreciate if the care could be given by one team. Older patients with heart failure seemed to adjust to their life changes better than younger patients affected by heart failure. Caregivers expressed need to understand the illness milestones and the disease progression. They wanted to be made aware of what would be a concerning point along the illness course or what resources would be needed by the patient [8].

There were some varied responses when it came to the end of life discussion. Some patients wanted to know all about the future course of heart failure and others did not want to talk about the future, as they saw it as a burden to their caregivers. Many expressed the need for counseling to deal with the uncertainty of the disease. Both patients and caregivers posed questions whether any treatments can be done to alleviate symptoms that develop as the disease advances. Mostly all the patients expressed need for their primary physician to be familiar with

their disease course. Caregivers expressed they wanted to be included more in the process and have better communication with the team. A team approach was well received by caregivers and patients alike. They felt as though immediate intervention once the diagnosis of heart failure was made would assist both parties in adjusting to the disease. Only 4 patients did not want a team approach as they did not want their treatment to change while 2 patients thought a care team would impeded on their independence.

What was the important point of this study? First there has not been a well-developed plan of living with heart failure, published for literature. Second, the patients and caregivers expressed need for guidance, especially on what to expect as the disease progresses. The understanding of symptoms patients will experience on a daily basis was the third point. Incorporating advanced care planning would assist on providing a prospective about the uncertainties of heart failure [8].

PAL-HF, a study held by Duke University by the palliative care division, explored palliative care and heart failure patients. They found that selected patients with heart failure maybe eligible for aggressive therapies such as cardiac transplant and mechanical devices. While the treatments are promising, they are not suitable for all heart failure patients. Many heart failure patients are elderly with co morbidities that may not be eligible to undergo such treatments. This study recognized the need for palliative care as a standard of care for the heart failure patient. As the heart failure disease progresses, it leads to a poor quality of life and carries a high rate of mortality. This study introduces palliative care as a routine part of the heart failure patients' plan of care. They identified several challenges when introducing palliative care into the treatment plan. The first challenge they came across was the unpredictable trajectory of life with heart failure. The second recognized challenge is lack of formalized training for the physicians who specialize in heart failure. They found that nurses are more likely to have formalized training in palliative care rather than the physicians. The study revealed that clinicians experienced turmoil when the discussion of palliative care is brought up as they fear being viewed as giving up on the patient. This study points out that there has been limited studies about heart failure and the benefits of palliative care. There have been many pilot studies that have shown how palliative care improves the quality of life and alleviates symptoms of oncology patients. Heart Failure patients have the opportunity to benefit from symptom relief and a better quality of life once palliative care is introduced. Some of the symptoms that have been shown to decrease, once palliative care is initiated into the patients plan of care are fatigue, anxiety, depression, nausea and dyspnea.

The Duke University study was funded by the National Institute of Nursing Research. The PAL-HF study evaluated a multidimensional palliative care intervention and how it improves health-related outcomes. This is compared to standard evidence-based care for heart failure patients with high short term mortality. The study consisted of a controlled, 2 arms, and single centered trial that included 200 advanced heart failure patients with more than 50% predicted 6 month mortality. The patients were placed in randomized groups that included a palliative care intervention or routine care. The palliative care intervention group's treatments focused on spiritual, relief of symptoms and advanced planning. The intervention lasted 6 months. There was a multidisciplinary team approach which made it difficult to do a double blinded trial. The patients in both treatment groups were studied until their death or the end of the study.

Patients considered for this study were either currently hospitalized with acute heart failure or those who were discharged within a 2 week

time frame. All the patients needed to meet the inclusion criteria set forth by this study. One inclusion factor was an ESCAPE (Evaluation Study of Congestive Heart Failure and Pulmonary Artery Catheterization) score of ≥ 4 which indicates >50% predicted mortality within 6 months. Exclusion for this study included those who were awaiting heart transplant or who received ventricular assist devices [9].

The treatment plan for the routine care patient group was set forth by a cardiology team with heart failure expertise. Their plan of care was evidence based treatments and focused on mood and sleep disorders. Once they were discharged they followed up with either the heart failure cardiologist or Nurse Practitioner. The follow up appointments continued with evidence based practices along with the review of the patient's adherence to the medical regime. Monitoring for end organ damage was also recorded.

The Palliative care intervention team approach stemmed from a NP, who was the core of this group. The NP worked with a palliative care and hospice board certified physician and a trained counselor. The cardiology team was the same team for both the routine care and intervention groups. Palliative care for intervention group was in conjunction with the cardiology team but it did not involve cardiology based palliative care interventions. During the enrollment of the intervention candidates the NP performed standardized assessments to determine the presence of common heart failure symptoms. If symptoms were identified they were managed by the PAL-HF team using algorithms to maintain standardization of treatment. Patients in the intervention group were provided with an educational hand out, PAL-HF Heart Failure Relief Medication, this provided information for the management of symptoms at home using typical medications for heart failure. Some of the medications were morphine elixir, SL (Sublingual) nitroglycerine and diuretics.

Patients were screened for psychosocial symptoms such as depression and anxiety using the Hospital Anxiety and Depression Scale (HADS). Patients who screened positive for either depression or anxiety received a more in depth screening using an algorithm to determine if a mental health referral and or medications were needed. A spiritual assessment was done on their intervention patients by the NP during the initial assessment. The FICA spiritual history tool was used (Faith and beliefs, Importance to life and health, Community religious and spiritual and A how the patient would like spirituality to be addressed by the health care team). If any needs were identified the NP shared with the PAL-HF team. End of life preparations were also addressed with the intervention patients. They received 3 one hour sessions a week apart. Each weekly session focused on different topics such as review and accomplishments, proudest moments and cherished times during session 1. Forgiveness, things they would have done differently and things left unsaid/undone were the focus of session 2. Lessons learned, learned heritage and legacy rounded out the third session. The sessions were facilitated by a trained counselor using questions outlined in a training module [9]. Goals of care were discussed and initiated by the patient. Goals were established and guided by the patient. These goals were revisited by the PAL-HF team periodically to assess for changes. The PAL-HF NP used the OncoTalk curriculum to maintain standardization with the intervention patient group. Once the 6 month trial was completed the PAL-HF NP continued to contact the intervention patients every 3 months to provide continued support. When a patient death occurred, the team reached out to the main caregiver approximately 6 weeks post death. An After Death Bereaved Family Member Interview- Hospice version would take place with consent of the caregiver. The questions assess the

overall quality of life, family and patient centered care. The data collected was used to assess the estimate cost and utilization of resources for the patient care [9].

The purpose of this study was to capture a more traditional heart failure patient's survival course. The only study that the PAL-HF study considered to be compared to would be a study that showed increased survival of lung cancer patients once palliative care was introduced. The PAL-HF study placed a great emphasis on the quality of life component rather than on the hospitalizations or death. This study expressed that palliative care does not hasten death. Due to the high risk patients entered into this trial, the team expected a 50% mortality rate by the end of the 6 month study. Researchers demonstrated the need for evidence using randomized trials for palliative care interventions to identify heart failure patients that may benefit [9].

The research team provided empirical data that supported the cost effectiveness and efficacy of introducing palliative care treatments to improve the quality of life in end stage heart failure patients. Some challenges they need to overcome are limited access and interventions of palliative care into heart failure treatment plans [9].

A European study describes palliative care as a specialized medical care targeting patients living with life threatening conditions. The goal of palliative care is to promote physical and psychosocial health which in turn will lead to an improvement of the quality of life for the patient and their family/caregiver. The study team felt that a way to reach their objectives they must place emphasis on these three areas:

- 1). Alleviation of control of symptoms and side effects of either the disease and/or curative treatments.
- 2). Timely and continuous update communication of treatment goals between physicians, patients and their families.
- 3). Efficient psychological, social and spiritual support of both the patient and their families throughout the course of illness trajectory [10].

In this study they recognize three barriers of initiating palliative care into the heart failure patient's plan of care. These barriers are uncertain prognostication, sudden death of a patient and the variety of treatment options and lack of information does not allow patients to be active in the decision making. These issues prevent the discussion of end of life care. Up until this study there has not been a standardized integrated plan of palliative care in Europe.

The study explores the difficulty of making a referral to palliative care services, as physicians find it difficult to determine the life expectancy of heart failure patients. Many patients do not get referred to palliative care due to this factor. Another stated reason is that the general public does not associate death with chronic diseases such as heart failure or COPD which make it difficult for physicians to initiate the conversation. There are many factors that go unmet when referring to palliative care services due to three major factors:

- 1). Reluctance of physicians to advocate expansion of specialist palliative care services
- 2). Obscurity of the roles of physicians and nurses in different specialties
- 3). Limited funding and infrastructures [10].

This European study has discussed barriers of implementing palliative care such as standardization of care is only published in German, Dutch, French, English, Hungarian and Spanish. Italian and

Swedish were excluded from this publication. There is lack of standardization and acceptance of palliative care for patients suffering with heart failure [10].

Conclusion

Palliative care remains a topic that is not well studied outside of oncology patients. Integrating Palliative care is a benefit that can help reduce anxieties, depression along with physical alignments of a heart failure patient. Palliative care has the benefits of being offered not only to the patient but to the caregiver as well. Heart failure not only affects the patients psychosocially and physically but it also takes a toll on the emotional well-being of the caregiver. Being able to have a palliative care plan implemented when the diagnosis of heart failure is given should be a standard of care lead by the medical team. As many of the reviewed studies have discussed, many cardiac physicians do not have the proper communication skills, education or trajectory of disease to discuss palliative care at an early time frame. Many patients do not want to discuss palliative care as they do not want to discuss their future as they fear their future will burden their caregivers. Although some of the studies did not show an increase in life span with palliative care implementation some did note a decrease in hospital visits and plans made for end of life care with some patients.

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