Volume 15 Issue 2 Year: 2018

# Integrating palliative care in heart failure: A review article

# Gülşah Çamcı <sup>1</sup> Sıdıka Oğuz<sup>2</sup>

#### **Abstract**

Millions of people have heart failure around world. Despite the advances in the care, heart failure has a poor prognosis. Palliative care offers patients a care which achieves symptom control with good quality of life. Palliative care is usually identified with cancer patients but individuals with heart failure also need palliative care. According to the World Health Organization, palliative care is needed mostly by patients with cardiovascular conditions followed by cancer patients. Patients with heart failure suffer from several symptoms, they have poor quality of life and it is difficult to estimate the course of their disease. Patients with heart failure, however, do not receive enough palliative care. Patients with heart failure should have palliative care integrated to their care to ensure that they receive palliative care services. The present study investigated palliative care models offered to patients with heart failures, and examined their outcomes. Several studies have found that heart failure patients who receive palliative care had better symptom management and quality of life and reduced hospitalizations.

Keywords: Palliative Care; Heart Failure; Model; Quality of life; Hospitalization.

#### Introduction

Chronic heart failure is a progressive disease (Gelfman, Kavalieratos, Teuteberg, Lala, & Goldstein, 2017:611) that impairs quality of life with high morbidity and mortality (Jaarsma et al., 2009:433; Riley & Beattie, 2017:81). In developed countries, heart failure affects about 1-2% of the adult population but this rate increases to ≥10% in individuals above 70 years of age (McMurray et al., 2012:803; Ponikowski et al., 2016:2129). One-sixth of the people have undiagnosed heart failure. The probability of heart failure at the age of 55 years is 33% in men and 28% in women. According to the latest data from Europe, inpatient heart failure patients represent 17% and outpatient heart failure patients represent 7% of the annual number of all-cause deaths (Ponikowski et al., 2016:2129) It is known that more than six million adults in the USA have heart failure. 870.000 individuals are diagnosed with heart failure every year (Gelfman et al., 2017:611) Heart failure is the leading cause of death in the States (Adler, Goldfinger, Kalman, Park, & Meier, 2009:2597). The Heart Failure Prevalence and Predictors in Turkey (HAPPY) study performed in Turkey found an absolute value of 2.9% for the prevalence of heart failure. The same study concluded that the prevalence of heart failure in the country was 6.9% when prevalence analysis was considered

<sup>1</sup>MSc., Marmara University Faculty of Health Sciences, Nursing Department of Internal Medicine, gulsah camci@hotmail.com

<sup>&</sup>lt;sup>2</sup> Assoc. Prof. Dr., Marmara University Faculty of Health Sciences, Nursing Department of Internal Medicine, soguz@marmara.edu.tr

without echocardiography. It is estimated that approximately 2 million and 424 adults have heart failure in Turkey (Değertekin et al., 2012:298). Patients diagnosed with heart failure have a mortality rate of 40% in the first year, which ranges from 45 to 75% in 5 years (Mert & Barutcu, 2012:219).

#### **Palliative Care**

Palliative care is derived from *palliare* in Latin, meaning conceal, alleviate or quench (Kahveci & Gökçınar, 2014:2). According to the World Health Organization, palliative care is a care that is aimed at providing care for the individuals with a life-threatening condition and to their families, to relieve the patient physically, psychologically and spiritually, and is provided by healthcare professionals and volunteers at home, hospitals, healthcare facilities and hospices (WHO, 2017).

### Palliative care;

- ✓ Provides relief from pain and other troublesome symptoms.
- ✓ Does not attempt to delay or accelerate death.
- ✓ Approves life and sees death as a normal process.
- ✓ Integrates spiritual and psychological aspects of patient care.
- ✓ Helps patients to maintain an active life until death.
- ✓ Engages in teamwork to meet the needs of the patient and family.
- ✓ Offers a support system to help the family cope with bereavement during the disease process of the patient and after death.
- ✓ These approaches will improve patient's quality of life and will affect the disease course favorably.
- ✓ It can be given together with other therapies that aim to prolong the patient's life expectancy such as radiation therapy or chemotherapy, helps to understand the required diagnostic investigations and prevents sad complications (WHO, 2017).

# Heart failure and Palliative care

Patients with heart failure are reported to experience more symptoms than patients with malignancies, have poor prognoses, are at more advanced ages, have impaired daily life activities and cognitive impairments (Fernandes & Guthrie, 2015:14; Jaarsma et al., 2009:433; McIlvennan & Allen, 2016:1010). According to the SUPPORT (Study to Understand Prognoses and Risks of Treatment) study in patients with heart failure, most patients who were expected to survive six months died within two days. Patients' 2-month survival rate was predicted to be 80% just 24 hours before death. These results indicate that it is difficult to foresee prognosis in patients with heart failure (Clement, Painter, & Shaffer, 2016:35). Worldwide, 40 million people require palliative care every year. Cardiovascular diseases represent 39% of this figure, followed by cancer and chronic lung conditions by 34 and 10%, respectively. However, 86% of the patients in need of palliative care can receive it (WHO, 2016). Forty-eight percent of cancer patients receive palliative care compared with 7% of patients with heart failure. Twenty-nine percent of patients with heart failure can receive palliative care for one week preceding death (Gadoud et al., 2014:113188). A retrospective study demonstrated that only 48 out of 940 heart failure patients were given palliative care. There was six days on average between death and hospitalization for patients who received palliative care (Bedet et al., 2015:255). A hospital reviewed medical files of 2647 patients with heart failure, noting that only 6% of heart failure patients were referred to palliative care (Greener, Quill, Amir, Szydlowski, & Gramling, 2014:1115).

Although palliative care was first originated in the malignancy setting, its scope is now extended to cover care of all individuals with any condition that limit life (Jaarsma et al., 2009:433). The current policy of the World Health Organization is to integrate palliative care into national healthcare systems (WHO, 2016).

Palliative care should be integrated into healthcare systems in order to improve symptom management and quality of life and reduce rehospitalizations of patients with heart failure (Strachan, Joy, Costigan, & Carter, 2014:134). According to the New York Heart Association

(NYHA), patients with class III and IV heart failure should be given palliative care. Symptom management is an important constituent of palliative care for patients with heart failure. The symptoms patients with heart failure experience more frequently are fatigue in 69-82%, pain in 63-80%, respiratory distress in 60-80%, anxiety in 49%, depression in 9-36% (Adler et al., 2009:2597; Mert & Barutcu, 2012:219) and palpitations in 59.4% (Oguz & Enç, 2008:462). Palliative care for patients with heart failure also involve communication, decision-making, continuous care (follow-up by phone calls, home visits, hospice etc.), supporting patient relatives, grief process, pacemaker, cardiac resynchronization therapy, implantable cardioverter defibrillators, left ventricular support device and transplantation (Ivany & While, 2013:441; Jaarsma et al., 2009:433; McIlvennan & Allen, 2016:1010; Wordingham, McIlvennan, Dionne-Odom, & Swetz, 2016:20). Symptom management for pain, dyspnea and depression is the primary targets for palliative therapy in patients with heart failure. Symptom management in these patients mostly involves diuretics and vasodilators. (Wensel & Rosielle, 2010:29) Palliative care practices with levels of evidence that should be undertaken for the symptoms commonly seen patients with heart failure including dyspnea, pain, depression and fatigue are provided in Table 1 (Adler et al., 2009:2597).

**Table 1:** Frequently Seen Heart Failure Symptoms and Palliative Care Options (Adler et al., 2009)

	Class of Recommendation					
Symptom	I	IIA	IIB	III	Insufficient	
Dyspnea	Loop diuretics without or with thiazides, Low-dose opioids Nitrates.	Inotropes Aquapheresis (if diuretic resistance) Hawthorn extract Exercise training Walking aids Breathing training	Oxygen (without hypoxia)	Benzodiazepines	Acupuncture Relaxation techniques Fans Nebulized opioids Psychotherapy Distractive auditory stimuli ie, music	
Pain	Opioids, Anginal pain: nitrates, ß-blockers, ranolazine, calcium channel blockers, coronary revascularization Bone pain: bisphosphonates.		Acupunctur e Music Exercise training	Nonsteroidal antiinflammatory drugs		
Depression	Serotonin-norepinephrine reuptake inhibitors, Tricyclic antidepressants, Selective serotonin reuptake inhibitors.	Psychological interventions: supportive therapy, counseling, or Cognitive behavioral therapy,	Exercise		Acupuncture	
Fatigue		Treat secondary causes (sleep apnea, anemia, infection, etc) Hawthorn extract Stimulants Exercise training		Increased rest and decreased of physical activity	Anti- inflammatory agents Nutritional supplements or appetite stimulants L-carnitine	

Treatments with high level of evidence in patients with heart failure are diuretics for dyspnea, nitrate and coronary revascularization for chest pain and selective serotonin reuptake inhibitors for depression (Table 1).

# Integrating palliative care in heart failure

Palliative care starts as soon as the patient is diagnosed with a severe or progressive chronic condition. As the disease progresses, the weight of palliative care versus life-extending care gradually increases. Besides, life-extending therapy should be halted when he patient wishes so or when the damage of the treatment outweighs the benefits, at which point the care is switched to hospice care. Palliative care services continue after death and family members are supported in their grief processes (Adler et al., 2009:2597) (Figure 1).

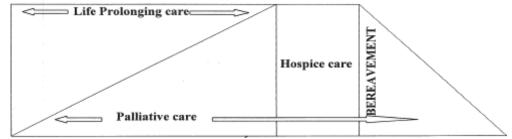


Figure 1: Palliative care integration model (Adler et al., 2009:2597)

Integration should be accomplished by adding palliative care activities to standard care in patients with heart failure (Jorgenson, Sidebottom, Richards, & Kirven, 2016:863). Palliative care models offered to heart failure patients are shown in Table 2.

Table 2: Palliative care models offered to patients with heart failure

Authors	Sample	Model Name	Outcome
Brännström and Boman (2014:1142) Bekelman et al. (2014:145)	A Randomized Controlled Study 36 Experiment 36 Controls Pilot Study 17 Heart failure	Palliative Advanced Home Care And Heart Failure Care (PREFER) Collaborative Care To Alleviate Symptoms And Adjust To Illness (CASA)	Improvements in total symptom burden, self-sufficiency and quality of life of 18, 17 and 24%, respectively, were found.  Patients' symptoms were controlled with collaborative care.
Dionne-Odom et al. (2014:995)	Experimental study 11 Patients 11 Caregivers	The ENABLE Model (Educate, Nurture, Advise, Before Life Ends)	Although feasibility and efficacy results are positive, it is suggested that it can be more effective when given to patients and caregivers earlier.
Sidebottom, Jorgenson, Richards, Kirven, and Sillah (2015:134)	A Randomized Controlled Study 116 Controls 116 Experiment	Standard Care Palliative Care	A short-term improvement occurred in quality of life and depression symptoms.
Yu et al. (2015:1593)	A Randomized Controlled Study 90 Experiment 88 Controls	Nursing Supported Transitional Care	Although the patients in the experiment group had fewer rehospitalizations in six weeks and had lower mortality, no significant relationship was found between the experiment and control groups with respect to mortality, rehospitalizations and survival
Wong et al. (2016:1)	A Randomized Controlled Study 43 Experiment 41 Controls	Transitional Palliative Care Model	Symptom control was better and there were fewer rehospitalizations.

The randomized, controlled study by Brännström and Boman (2014:1142) included 36 patients in the experiment group and 30 controls, both with heart failure. Patients in the experiment group were given Palliative Advanced Home Care and Heart Failure Care (PREFER). Patient-centered palliative care was given to heart failure patients by a multidisciplinary team. Patients were evaluated after one, three and six months. They were provided with symptom management and social and psychological support. Home visits were paid and phone calls were made with them. At the end of the study, there was a decrease in nausea, and total symptom burden, self-sufficiency and quality of life improved by 18, 17 and 24%, respectively in the group that received palliative care. PREFER model was also found to be a cost-effective model compared with standard care (Sahlen, Boman, & Brännström, 2016:296) (Table 2).

In their pilot study with 17 patients, Bekelman et al. (2014:142) used the Collaborative Care to Alleviate Symptoms and Adjust To Illness (CASA) model in patients with heart failure. The patients were offered symptom management, psychological care and collaborative care. It was found to be a model that is applicable for patients. Symptoms were controlled to a better extend with the collaborative care given to the patients (Table 2).

Dionne-Odom et al. (2014:995) used the ENABLE Model (Educate, Nurture, Advise Before Life Ends) in 11 heart failure patients and 11 caregivers. With the ENABLE model, the patients and caregivers were offered support in problem-solving, symptom management, self-care, communication, care coordination, decision-making and further care through phone calls and face-to-face meetings. Although feasibility and efficacy results are positive in the study, it is suggested that it can be more effective when given to patients and caregivers earlier (Table 2).

The randomized, controlled study by Sidebottom et al. (2015:134) included 116 patients in the experiment group and 116 controls, both with heart failure. The patients in the control group received standard care while those in the experiment group were given palliative care. The latter patients were paid visits, during which they were evaluated from emotional, spiritual and psychosocial aspects, and necessary guidance was made. The required care was given through team collaboration. Changes in the current or future care were reviewed and necessary planning for further care was made together with the patient. A short-term improvement was seen in depression symptoms, symptom burden and quality of life in patients who received palliative care (Table 2).

The randomized, controlled study by Yu et al. (2015:1593) in Hong Kong enrolled 90 patients in the experiment group and 88 controls, both with heart failure. The patients in the control group received standard care while those in the experiment group received nurse-assisted Transitional Care. Patients in the experiment group were visited at their homes every other week, regular phone calls were made and training on optimal healthcare services, supportive services and self-care were given. In this study, the patients in the experiment group had fewer rehospitalizations after six weeks and lower mortality after nine months, but no significant relationship was found between the experiment and control groups with respect to mortality, rehospitalizations and survival (Table 2).

The randomized, controlled study by Wong et al. (2016:1) examined 43 patients in the experiment group and 41 controls, both with heart failure. The patients in the experiment group were given Transitional Palliative Care. They were followed up every week for the first five weeks following discharge, after which the patients were followed up by monthly phone calls and home visits for up to 12 weeks. Nursing case managers supported by multidisciplinary care performed applications. Patients were offered symptom management and support services for advanced treatment. Patients who received Transitional Palliative Care Model had better symptom control and fewer rehospitalizations (Table 2).

# Conclusion

Studies have demonstrated decreased hospitalizations and improved symptom control and quality of life with the palliative care given to the patients with heart failure. Continued palliative care should be ensured through phone calls, home or hospital visits. More evidence-based studies for symptom control in heart failure patients should be performed.

Funding No funding was received for this project.

**Conflict of interest** All authors declare that they have no competing interests.

#### References

- Adler, E. D., Goldfinger, J. Z., Kalman, J., Park, M. E., & Meier, D. E. (2009). Palliative care in the treatment of advanced heart failure. *Circulation*, 120(25), 2597-2606.
- Bedet, A., Garçon, P., Boulogne, M., Richard, J., Opatowski, L., Moubarak, G., . . . Cador, R. (2015). Characteristics of the population hospitalized for advanced and terminal heart failure and experiences in palliative caring in the Intensive Care Unit of cardiology. *Paper presented at the Annales de cardiologie et d'angeiologie.* 64(4), 255-262. doi:10.1016/j.ancard.2015.02.002
- Bekelman, D. B., Hooker, S., Nowels, C. T., Main, D. S., Meek, P., McBryde, C., . . . Heidenreich, P. A. (2014). Feasibility and acceptability of a collaborative care intervention to improve symptoms and quality of life in chronic heart failure: mixed methods pilot trial. *Journal of palliative medicine*, 17(2), 145-151. doi: 10.1089/jpm.2013.0143
- Brännström, M., & Boman, K. (2014). Effects of person-centred and integrated chronic heart failure and palliative home care. PREFER: a randomized controlled study. *European journal of heart failure*, 16(10), 1142-1151. doi:10.1002/ejhf.151
- Clement, L., Painter, Q., & Shaffer, J. A. (2016). Meeting the Unmet Needs of Aging Heart Failure Patients: A Role for Palliative Care. *Current Cardiovascular Risk Reports, 10*(11), 35. doi: 10.1007/s12170-016-0515-4
- Değertekin, M., Çetin Erol, D., Ergene, O., Tokgözoğlu, L., Aksoy, M., Erol, M. K., . . . Mutlu, B. (2012). Türkiye'deki kalp yetersizliği prevalansı ve öngördürücüleri: HAPPY çalışması. *Türk Kardiyol Dern Arş, 40*(4), 298-308.
- Dionne-Odom, J. N., Kono, A., Frost, J., Jackson, L., Ellis, D., Ahmed, A., . . . Bakitas, M. (2014). Translating and testing the ENABLE: CHF-PC concurrent palliative care model for older adults with heart failure and their family caregivers. *Journal of palliative medicine*, 17(9), 995-1004. doi: 10.1089/jpm.2013.0680
- Fernandes, S., & Guthrie, D. M. (2015). A comparison between end-of-life home care clients with cancer and heart failure in Ontario. *Home health care services quarterly, 34*(1), 14-29. doi: 10.1080/01621424.2014.995257
- Gadoud, A., Kane, E., Macleod, U., Ansell, P., Oliver, S., & Johnson, M. (2014). Palliative care among heart failure patients in primary care: a comparison to cancer patients using English family practice data. *PloS one*, 9(11), e113188. doi:10.1371/journal.pone.0113188
- Gelfman, L. P., Kavalieratos, D., Teuteberg, W. G., Lala, A., & Goldstein, N. E. (2017). Primary palliative care for heart failure: what is it? How do we implement it? *Heart failure reviews, 22*(5), 611-620. doi 10.1007/s10741-017-9604-9
- Greener, D. T., Quill, T., Amir, O., Szydlowski, J., & Gramling, R. E. (2014). Palliative care referral among patients hospitalized with advanced heart failure. *Journal of palliative medicine*, 17(10), 1115-1120. doi: 10.1089/jpm.2013.0658
- Ivany, E., & While, A. (2013). Understanding the palliative care needs of heart failure patients. *British journal of community nursing*, 18(9), 441-445.
- Jaarsma, T., Beattie, J. M., Ryder, M., Rutten, F. H., McDonagh, T., Mohacsi, P., . . . Metra, M. (2009). Palliative care in heart failure: a position statement from the palliative care workshop of the Heart Failure Association of the European Society of Cardiology. *European journal of heart failure*, 11(5), 433-443.

- Jorgenson, A., Sidebottom, A. C., Richards, H., & Kirven, J. (2016). A description of inpatient palliative care actions for patients with acute heart failure. *American Journal of Hospice and Palliative Medicine*®, 33(9), 863-870.
- Kahveci, K., & Gökçınar, D. (2014). Palyatif bakım. İstanbul: Nobel Tıp Kitabevi.p.2
- McIlvennan, C. K., & Allen, L. A. (2016). Palliative care in patients with heart failure. bmj, 353, i1010.
- McMurray, J. J., Adamopoulos, S., Anker, S. D., Auricchio, A., Böhm, M., Dickstein, K., . . . Gomez-Sanchez, M. A. (2012). ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure 2012. *European journal of heart failure*, 14(8), 803-869.
- Mert, H., & Barutcu, C. D. (2012). Kalp Yetersizliğinde Palyatif Bakım. TAF Preventive Medicine Bulletin, 11(2), 219-224.doi:10.5455/pmb.1-1308553974
- Oguz, S., & Enç, N. (2008). Symptoms and strategies in heart failure in Turkey. *International nursing review*, 55(4), 462-467.
- Ponikowski, P., Voors, A. A., Anker, S. D., Bueno, H., Cleland, J. G., Coats, A. J., . . . Jankowska, E. A. (2016). 2016 ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure: The Task Force for the diagnosis and treatment of acute and chronic heart failure of the European Society of Cardiology (ESC) Developed with the special contribution of the Heart Failure Association (HFA) of the ESC. *European heart journal*, 37(27), 2129-2200. doi:10.1093/eurheartj/ehw128.
- Riley, J. P., & Beattie, J. M. (2017). Palliative care in heart failure: facts and numbers. *ESC Heart Fail*, 4(2), 81-87. doi:10.1002/ehf2.12125
- Sahlen, K.-G., Boman, K., & Brännström, M. (2016). A cost-effectiveness study of person-centered integrated heart failure and palliative home care: based on a randomized controlled trial. *Palliative medicine*, 30(3), 296-302.
- Sidebottom, A. C., Jorgenson, A., Richards, H., Kirven, J., & Sillah, A. (2015). Inpatient palliative care for patients with acute heart failure: outcomes from a randomized trial. *Journal of palliative medicine*, 18(2), 134-142. doi: 10.1177/0269216315618544
- Strachan, P. H., Joy, C., Costigan, J., & Carter, N. (2014). Development of a practice tool for community-based nurses: the Heart Failure Palliative Approach to Care (HeFPAC). European Journal of Cardiovascular Nursing, 13(2), 134-141. doi: 10.1177/1474515113519522.
- Wensel, D., & Rosielle, D. A. (2010). Cardiac Palliative Care Issues *Palliative Care*. Springer. pp. 29-36 doi: 10.1007/978-1-60761-590-3\_5.
- WHO. (2016). http://www.who.int/ncds/management/palliative-care/infographic\_palliative\_care\_EN.pdf?ua=1%20-. Date accessed: 1 Semptember 2017
- WHO. (2017). Worldwide Palliative Care, and World Health Organization. "Global atlas of palliative care at the end of life." WHO: Ginebra (2014) http://www.who.int/cancer/publications/palliative-care-atlas/en/. Date accessed: September 1, 2017
- Wong, F. K. Y., Ng, A. Y. M., Lee, P. H., Lam, P.-t., Ng, J. S. C., Ng, N. H. Y., & Sham, M. M. K. (2016). Effects of a transitional palliative care model on patients with end-stage heart failure: a randomised controlled trial. *Heart*, heartjnl-2015-308638. doi:10.1136/heartjnl-2015-308638
- Wordingham, S. E., McIlvennan, C. K., Dionne-Odom, J. N., & Swetz, K. M. (2016). Complex care options for patients with advanced heart failure approaching end of life. *Current heart failure reports*, 13(1), 20-29. doi:10.1007/s11897-016-0282-z
- Yu, D. S., Lee, D. T., Stewart, S., Thompson, D. R., Choi, K. C., & Yu, C. M. (2015). Effect of Nurse-Implemented Transitional Care for Chinese Individuals with Chronic Heart Failure in Hong Kong: A Randomized Controlled Trial. *Journal of the American Geriatrics Society*, 63(8), 1583-1593.