

# Impact of a Palliative Care Education Module in Patients With Heart Failure

Shelley L. Thompson, DNP, NP-C<sup>1,2</sup> , Cary Ward, MD<sup>1</sup>, Anthony Galanos, MD<sup>1</sup>, and Margaret Bowers, DNP, FNP-BC, AACC<sup>1,2</sup>

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## Abstract

**Background:** Heart failure (HF) impacts 6.2 million American adults. With no cure, therapies aim to prevent progression and manage symptoms. Inclusion of palliative care (PC) helps improve symptoms and quality of life. Heart failure guidelines recommend the inclusion of PC in HF therapy, but referrals are often delayed. **Objective:** Introduce PC to patients with HF and examine the impact on PC consults, readmission, mortality, and intensive care unit (ICU) transfers. **Methods:** Patients (n = 60) admitted with HF to an academic hospital were asked to view a PC educational module. A number of PC consults, re-admissions, mortality, and transfers to the ICU were compared among participants and those who declined. **Results:** Nine patients in the intervention group (n = 30) requested a PC consult (P = .042) versus 2 in the usual care group (n = 30; P = .302). There was no statistically significant difference in readmissions, mortality, or ICU transfers between groups. **Conclusions:** Palliative care education increases the likelihood of PC utilization but in this short-term project was not found to statistically impact mortality, re-admissions, or transfers to higher levels of care.

## Keywords

heart failure, palliative care, patient care planning, quality of life, patient education

## Introduction

Over 6.2 million adults are living with heart failure (HF) in the United States and approximately half will die in the next 5 years. The prevalence of HF is projected to increase by 46% by 2030, which equates to over 8 million adults with HF.<sup>1</sup> Heart failure is the number one diagnosis-related group for Medicare admissions<sup>2</sup> and the cost of HF care totals almost 31 billion dollars a year.<sup>1</sup>

Despite advances in HF management, it remains incurable. Therapies are aimed at halting progression of disease and treating symptoms, which place high demands on patients, care givers, and the health-care system.<sup>3</sup> Symptoms are both physical and psychological, including pain, dyspnea, fatigue, edema, poor appetite, nausea, insomnia, anxiety, and depression.<sup>2,4-9</sup> Waxing and waning of symptoms and an unpredictable disease trajectory may lead to feelings of poor quality of life (QOL) and spiritual distress.<sup>2-8</sup> Even when controlling for advanced age, in comparison to patients with cancer, patients with HF had a larger burden of untreated symptoms, especially dyspnea.<sup>6</sup>

These common symptoms may be alleviated through palliative care (PC) measures.<sup>2,5,9-14</sup> Palliative care may be defined as interventions that improve the QOL for patients and families who are challenged with chronic or life-threatening illness. Goals of PC involve early identification of symptoms, accurate assessment, and treatment of physical, psychosocial, and spiritual issues. Palliative care functions not only to relieve

symptoms but also to affirm life and regard dying as part of life; however, it does not expedite or delay death. A team approach is utilized to enhance QOL and provide support to patients and families, both during illness and the bereavement process.<sup>15</sup>

The World Health Organization advocates for the use of PC to improve the QOL for both patients and families by addressing the issues associated with life-threatening illness, through prevention and treatment of pain, physical, psychosocial, and spiritual problems.<sup>15</sup> Heart failure certainly meets those criteria. Major HF associations, including the Heart Failure Society of America, American College of Cardiology, The American Heart Association, and European Society of Heart Failure, all recommend PC to become a part of standard care for patients with HF and it is a class IB recommendation in the HF treatment guidelines.<sup>16</sup>

Due to the complex nature of HF care, need for personalized interventions, patient-centered care planning, and need for communication regarding limited treatment options, PC seems to be a good fit<sup>8</sup> but is underutilized. It is estimated over 30% of

<sup>1</sup> Duke University Hospital, Durham, NC, USA

<sup>2</sup> Duke University School of Nursing, Durham, NC, USA

## Corresponding Author:

Shelley Thompson, DNP, NP-C, Duke University Hospital, 2301 Erwin Road Durham, NC 27710 USA.

Email: shelley.thompson@duke.edu

patients with HF could be assisted through PC.<sup>12</sup> For a population of over 6.2 million US adults, this translates to almost 2 million patients who may benefit. This does not include caregivers, who should be included in the assessment and interventions.<sup>17</sup>

Too often, patients and providers fail to think of HF as a serious, terminal illness.<sup>18</sup> Therefore, patients can go untreated or with symptoms poorly managed.<sup>2</sup> Given the variable disease trajectory, it may be difficult to estimate survival. Less than 50% of physicians accurately predict survival in HF,<sup>19</sup> making the timing of PC referrals a challenge. Patients and families may not comprehend the prognosis and may underestimate the severity of the disease,<sup>20</sup> making them less likely to pursue PC. Provider attitudes, siloed care, knowledge gaps, lack of research in PC for HF, and lack of PC programs accessible to those with HF can be an obstacle.<sup>3,21</sup>

There are few trials examining the incorporation of PC into HF care. Despite this, trial results are remarkably similar. When PC was incorporated into HF care, all trials reported improvement in patient symptom burden and QOL was improved.<sup>2,5,10-14,22</sup> Moreover, some studies even noted an improvement in physical health after PC services were introduced.<sup>22,23</sup> None of the trials noted negative impacts such as increased mortality, hospital days, worsened symptoms, or caregiver burden on those who received PC.<sup>2,10,24,25</sup> Both patients and caregivers reported increased QOL and satisfaction.<sup>10-13,25</sup> Health-care dollars utilized for PC were lower than for standard HF care, even with receiving more services.<sup>12,13</sup> This may be due in part to reduced hospital readmissions.<sup>24,26</sup>

Despite the clear benefits of PC in HF, it remains underutilized. A recent study of HF patients showed the median time from PC consult to death was 6 days and the median time from comfort care orders to death was 24 hours.<sup>27</sup> Another study showed HF patients spent an average of 22 days in hospice, with nearly half of those dying within the first week.<sup>28</sup> These data suggest referrals to PC and hospice for patients with HF are coming too late.

One obstacle to the use of PC in HF is lack of education.<sup>3,21</sup> Patients need education about PC services before they can be utilized. Mobile applications have been proven to be an effective option for education<sup>29</sup> and are a convenient and efficient way to provide education.<sup>30</sup> Prior studies note the benefits of using mobile applications to help individualize care planning and begin collaborative conversations.<sup>31</sup> Disease-specific interactive applications may be more helpful than nontargeted tools in improving QOL and patient outcomes.<sup>32</sup> Use of educational apps may lead to more open discussions among patients, families, and providers about PC and potentially lead to earlier referrals.

The focus of this pilot study was to introduce a PC education module on a mobile device, screen patients for inclusion into PC based on their responses and incorporate PC at an earlier time. For patients who elected to participate in the intervention compared to those who elected to proceed with usual care (UC), secondary goals included decreased 30-day readmission

rate and 30-day mortality, and decreased a number of transfers to intensive care units (ICUs).

## Methods

Prior to the start of the study, approval was obtained from the institutional review board. Verbal consent was obtained from participants prior to the introduction of the intervention.

## Intervention

The intervention for this project is PCforMe, an educational, interactive mobile application for use by both patients and caregivers. It educates the user about PC, as an “extra layer of support” in addition to UC and how PC differs from hospice.<sup>33</sup> It is geared toward chronic disease and is not specific to HF. The program describes symptom management and asks the user what symptoms are most bothersome. The participant can use the provided checkboxes to identify symptoms or responses can be typed into allotted spaces. It helps users identify ways PC could be of assistance, such as counseling or helping with emotional or spiritual issues, in addition to symptom management. Furthermore, it raises questions about living wills, health-care power of attorney, and resuscitation status, which patients can use to begin discussions with their care team and family. PCforMe also helps users identify hopes and worries about the future. At the end of each PCforMe session, a “passport” is printed which summarizes the patient replies made during the session. This passport may be shared with the family and the care team to stimulate further discussion. Users are also provided a unique code allowing them to access the program in the future. This is particularly helpful as disease trajectories and symptoms change. The module takes approximately 30 minutes to complete, either in a single session or over several sessions.

For the intervention, HF patients meeting criteria were approached and offered the PCforMe module on an iPad. Patients were informed no sensitive information would be collected, completing the module was voluntary and would not impact care received. If the patient or caregiver desired a PC consult, efforts were made to place it during the admission. If it could not be completed during the admission, an outpatient referral was placed. Patients who elected to participate were placed in the intervention group (IG) and those who declined were in the UC group.

Data from the electronic health record (EHR) were examined 5 weeks after the last participant was discharged from the hospital. The 2 groups were compared regarding the number of PC consults placed, 30-day readmissions, 30-day mortality, and ICU transfers. Additionally, data on age, race, gender, ejection fraction (EF), New York Heart Association (NYHA) class, admission sodium, creatinine, and hematocrit, code status, and discharge disposition were collected to help compare similarities and differences between groups.

## Participants

A convenience sample of patients admitted to the cardiology floors of an academic medical center with HF with preserved EF or HF with reduced EF were screened for inclusion in the intervention during October and November of 2018. Patients who were already receiving PC services or being actively evaluated for heart transplantation or mechanical circulatory support were not included. Those who did not speak English as their primary language were excluded, as the education module is only available in English. A total of 60 eligible patients were approached for inclusion in the study.

## Analysis

Before patient recruitment began, the sample size was evaluated by calculating a power analysis. Based on prior HF admission and PC consult rates for 2017, it was determined 188 patients would be needed to obtain a 95% confidence interval. Given time constraints and that this was a pilot project, a sample size of 60 was utilized.

This study used a retrospective, 2-arm design, with the EHR used to gather data. After the intervention was completed, the number of PC consults placed, 30-day readmissions, 30-day mortality, and ICU transfers were examined and compared among the 2 groups. Data on patients' age, gender, race, EF, NYHA HF class, admission sodium, creatinine, and hematocrit and code status were collected to assist in comparing group composition.

Comparison of the IG and the UC group's PC consults, ICU transfers, 30-day readmission rates, and in-house mortality rates were done using a Fisher exact test. Demographic data, including age, gender, EF, NYHA class, and admission laboratories were compared utilizing independent *t* tests and  $\chi^2$  tests to assess group composition.

## Results

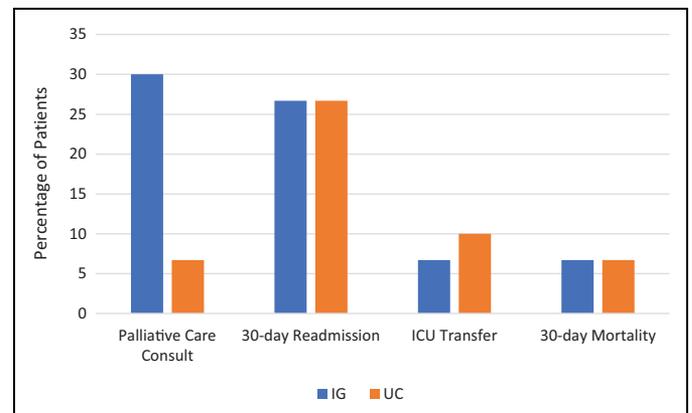
Group composition was compared according to age, gender, race, NYHA class, and EF utilizing descriptive statistics and a *t* test for equality of means. There were no significant differences among groups based on the age ( $P = .264$ ), gender ( $P = .796$ ), race ( $P = .488$ ), NYHA class ( $P = .520$ ), or EF ( $P = .965$ ). Furthermore, groups appeared similar in terms of disease severity based on admission sodium ( $P = .223$ ), hematocrit ( $P = .301$ ), and creatinine ( $P = .405$ ; see Table 1).

Patients in the IG ( $n = 30$ ) were compared to patients in the UC group ( $n = 30$ ) on the number of PC consults placed, 30-day readmission, ICU transfer, and 30-day mortality using Fisher exact tests (see Figure 1). A significantly higher percentage of patients in the IG group had PC consults ( $P = .042$ ;  $\Phi = .302$ ) compared to the UC group. The groups were similar regarding readmission, mortality, and ICU transfers. Of note, the mortalities in the IG occurred after each patient was discharged. Each of the mortalities in the UC group occurred in the hospital.

**Table 1.** Demographics for IG and UC Groups.

Variables	IG	UC	P Value
Age (years), mean (SD)	68.67 (12.37)	72.20 (11.91)	.264
Gender, female, n (%)	15 (50.0)	17 (56.7)	.796
Race, n (%)			.488
African American	15 (50.0)	13 (43.3)	
Hispanic	1 (3.3)	0 (0.0)	
White	14 (48.7)	17 (56.7)	
NHYA class, n (%)			.520
2	1 (3.3)	0	
3	23 (76.7)	22 (73.3)	
4	6 (20)	8 (26.7)	
EF, mean (SD)	33.00 (14.48)	32.83 (14.84)	.965
Sodium, mean (SD)	136.6 (3.48)	135.3 (4.61)	.223
Hematocrit, mean (SD)	36.02 (7.06)	34.16 (6.77)	.301
Creatinine, mean (SD)	1.93 (1.03)	1.75 (0.65)	.405

Abbreviations: EF, ejection fraction; IG, intervention group; SD, standard deviation; UC, usual care.



**Figure 1.** Comparison of intervention and usual care group results in percentages.

During the intervention in 2018, the hospital had 67 patients admitted with HF with 11 PC consults or 16.4%. In the same time frame in 2017, the hospital had 80 patients admitted with HF and 6 PC consults or 7.5%. Based on this data, it appears the intervention had a significant impact on the number of PC consults, with a greater than 200% increase.

After viewing the module, patients had the opportunity to discuss their thoughts with project personnel. During this time, patients verbalized only positive comments about the module. All patients and caregivers felt the module was helpful and non-threatening. Several patients stated they never heard of PC while a few others thought it was the same as hospice. A few patients asked to view the module more than once. All but 1 patient felt they learned something new during the module and would be open to viewing it again. Multiple patients stated they felt the information presented was helpful and would be interested in PC services in the future, but stated it was not needed at the time, as their symptoms were well-controlled.

The majority of patients stated they found it easy to navigate through the module using an iPad. Those who were less familiar with technology and with limited literacy required some assistance from project personnel to navigate through the screens but were able to hear the content clearly.

## Discussion

This quality improvement project raised awareness of the need to educate patients and caregivers about PC. Many patients and/or caregivers thought PC and hospice were interchangeable and after viewing the module verbalized an enhanced understanding of the difference. After utilizing the module, 9 patients recognized they could benefit from PC services and requested a consult.

All patients and caregivers felt the module was helpful and non-threatening. Several patients asked to view the module more than once. All but 1 patient felt they learned something new during the module and would be open to viewing it again in the future.

Use of the module opened doors for discussions about goals of care and future care planning. After meeting with the PC team for several days, 1 patient and family changed code status to do not resuscitate and elected to proceed with PC services but still wanted aggressive care up to the point of cardiopulmonary arrest. The patient was discharged to a skilled facility for rehab and died 2 days later.

Multiple patients did not feel they needed PC services at the time of viewing the module. Several of these patients were considered NYHA stage IV and a few were on chronic inotropic support. This reinforces prior knowledge that patients often underestimate the severity of their illness.<sup>34</sup> In the same vein, providers can have difficulty estimating survival<sup>19</sup> and none of the patients in NYHA class IV HF had previously been referred to PC. During the project, a patient viewed as having stable NYHA class II HF requested a PC consult. The team was surprised as her symptoms seemed to be well-managed and it was her first hospitalization in 15 months, but the consult was provided. Both the patient and the PC team felt the time was valuable and the consult appropriate. To the surprise of the cardiology team, this “stable” patient died 6 weeks later.

As in other studies evaluating PC in HF, there was no impact on mortality in those who had a PC consult and no decrease in readmissions. Some past trials have noted decreased readmissions when followed by PC,<sup>10,12,24</sup> while others have noted no change.<sup>2,14</sup> But a compelling sequela of the intervention was greater than 200% increase in the number of PC consults from the same time frame in the previous year. Thus, the intervention impacted the collaboration between the PC and HF teams via increased referral rates.

In the future, the use of automatic triggers in the EHR to promote PC consults may be beneficial. These could be as simple as a trigger when admitting for decompensated NYHA classes III-IV HF, readmission in 30 days, or 3 admissions in 6 months.

While the patient screening and contact were conducted by 1 nurse practitioner, multiple members of the cardiology team expressed an interest in participating. The advanced practice provider (APP) team provided patient referrals for screening and was supportive in calling consults to the PC team if the patient requested. This study increased interest in the use of PC among the APP team and nurses. Numerous nurses and APP team members approached the project personnel stating how desperately this education was needed for patients with HF and suggested patients to screen for inclusion. Many of the APP team members asked how they could get involved in the project. Four of these APP team members are currently involved in carrying out the project on a larger scale.

Although patients admitted to the hospital benefit from the education and subsequent PC consults, it remains to be seen if the ideal location for this education is an inpatient or outpatient setting. Patients who are experiencing more symptoms may be more inclined to participate, while those whose symptoms are more well-controlled may be more likely to decline. Conversely, patients who are sicker may be less inclined to view the module due to increased symptom burden and patients who feel well may be more agreeable to participate. During the intervention, most patients declined due to being tired or not wanting to participate in research. A few declined due to the length of time required to complete the module.

It is unclear if the hospital is the ideal location for the presentation of this information; however, it was utilized by several NYHA class IV patients who were on home inotropes. Due to the severity of their illness, they were rarely seen in clinic and had frequent hospital admissions. Those patients, who can surely benefit, would be missed if the module were only to be offered in the clinic setting. The trial of the PCforMe module was completed in an outpatient clinic setting.<sup>33</sup> Further research is needed to determine the best setting for patients with HF but may include both inpatient and outpatient locales.

## Limitations

This was a small pilot project to determine potential inclusion into future standard care at an academic medical center. The small sample size was not at the recommended number for a confidence interval of 95%. Further study using a larger sample size is recommended, especially to help determine the impact on re-admissions, transfers to ICU, and mortality. Additionally, the results may have differed if completed in an outpatient setting instead of a hospital environment.

There was the possibility of selection bias with patients who had more symptoms declining to review or increased motivation to review the module; however, the results showed the IG and UC group were statistically similar. There was no significant difference in NYHA HF class, EF, or biomarkers, as indicators of advanced illness or disease severity.

While the groups were similar in demographics, the Hispanic population was under-represented. Four Hispanic patients were screened but excluded since they did not speak English. It

would be valuable to have educational materials available for Spanish-speaking patients and caregivers.

The educational module is still being evaluated by its creators and is not available for public use. While most found it easy to use, several patients who were unfamiliar with the use of iPads found it a bit difficult to navigate and required assistance to complete the module. Furthermore, those with limited literacy also required assistance to answer questions in the module and moving from screen to screen but were able to hear the teaching provided in the program. For these patients, a caregiver may assist the patient in completion of the educational module. For patients who are hard of hearing, use of earbuds may enhance the sound.

This was a short-term study over about 8 weeks. There is no follow-up scheduled to evaluate the long-term implications of the intervention.

## Conclusion

Heart failure is a challenging disease process with varied symptoms. Patients need early symptom management and education regarding their disease trajectory and prognosis. Palliative care services can assist in the management of symptoms, lead to an improved QOL, and reduce health-care costs. Education about PC can correct misconceptions and lead to the inclusion of services earlier in the disease process, but further research is needed to determine the impact on mortality and readmissions. The main point of this project was to demonstrate that targeted education promotes the inclusion of PC services in patients with HF. While the use of the educational module was helpful, education can be provided using a variety of methods. Including PC education is an easily sustainable intervention that can be low-cost.

This work can also be applied to patients with other chronic disease processes. Potential patients who may benefit from PC services include those with coronary artery disease not amenable to revascularization, chronic obstructive pulmonary disease, or chronic kidney disease. Patients with HF who have complications after mechanical circulatory support devices may also benefit.

All patients with chronic disease need palliation. Involving PC in standard HF care is a class IB recommendation in the HF guidelines.<sup>16</sup> Provision of education about PC for patients with chronic disease should be included in standard care. Regardless of how the information is disseminated, it is vital that it must be shared—it will benefit patients and may reduce health-care cost. Improving QOL and care for patients with HF was the goal of this initiative.

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## ORCID iD

Shelley L. Thompson  <https://orcid.org/0000-0001-8422-8624>

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