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Heart Failure and Palliative Care: Implications in Practice

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Abstract

The number of people with heart failure is continually rising. Despite continued medical advances that may prolong life, there is no cure. While typical heart failure trajectories include the risk of sudden death, heart failure is typically characterized by periods of stability interrupted by acute exacerbations. The unpredictable nature of this disease and the inability to predict its terminal phase has resulted in few services beyond medical management being offered. Yet, this population has documented unmet needs that extend beyond routine medical care. Palliative care has been proposed as a strategy to meet these needs, however, these services are rarely offered. Although palliative care should be implemented early in the disease process, in practice it is tied to end-of-life care. The purpose of this study was to uncover whether the conceptualization of palliative care for heart failure as end-of-life care may inhibit the provision of these services. The meaning of palliative care in heart failure was explored from three perspectives: scientific literature, health care providers, and spousal caregivers of patients with heart failure. There is confusion in the literature and by the health care community about the meaning of the term palliative care and what the provision of these services entails. Palliative care was equated to end-of-life care, and as a result, health care providers may be reluctant to discuss palliative care with heart failure patients early in the disease trajectory. Most family caregivers have not heard of the term and all would be receptive to an offer of palliative care at some point during the disease trajectory.

Introduction

The number of Americans with heart failure is on the rise, affecting more than 5.3 million people.[1] With the improvement in survival rates of myocardial infarction (MI) victims, comes a rise in disabling heart failure; within 6 years of an MI 22% of men and 46% of women are disabled with heart failure. The illness trajectory (and ultimately, the death trajectory) of heart failure is unpredictable.[2] Heart failure is typically characterized by periods of stability interrupted by episodes of acute exacerbation.[3, 4]

Although new life-prolonging treatments are continually being developed for heart failure, morbidity and mortality remain high. Between 30% and 50% of those newly diagnosed with heart failure die within the first year,[5,6] and according to the American Heart Association[1] many of these deaths are unexpected, as the incidence of sudden cardiac death is 6 to 9 times higher than in the general population. As heart failure progresses, the unpredictability of the disease becomes even more evident. In fact, the inability to predict the actual terminal phase of the disease[7] has resulted in few services beyond traditional medical management being offered to patients and families living with heart failure.[8]

The complexity of the course of illness is reflected in research on the care of persons with heart failure. Numerous studies of these patients have documented unmet needs, such as symptom management, difficulties performing activities of daily living, and psychosocial concerns, including lack of emotional support and feelings of social isolation.[9–13] Thus, there is a critical need for interventions with patients and their caregiving families across this complicated illness trajectory.

Palliative care is an obvious strategy to address the needs of heart failure patients.[14–16] It is important to note that in this context, the term palliative care does not connote care of the dying; rather, it is a holistic set of interventions designed to address the quality of life of families affected by life-limiting illnesses, whether needed for months or even years.[17] Although palliative care appears to be the evident approach for delivering critically needed supportive interventions across the trajectory of heart failure; less than 10% of persons with heart failure receive palliative care services.[8]

In our longitudinal study of spousal caregivers of heart failure patients (NIH/NINR; 1R15NR009976), wives expressed a number of care needs that were amenable to palliative care services. As in other studies,[8,10] referrals to the palliative care service were infrequent and often introduced at the point of terminal decline. The significance of the disconnect between the needs expressed by family caregivers and introduction of palliative care services became increasingly apparent as our study progressed. During interactions with

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health care providers, we realized that the term "palliative care" was commonly used synonymously with hospice care, therefore, referral to the palliative care service was reserved for advanced disease states in which death was imminent.

Palliative Care

One problem with utilization of palliative care for an unpredictable disease trajectory such as heart failure, is the conceptualization within the health care field that palliative care is a formal care delivery service introduced at end of life and not a philosophy of care[17] for a person who needs services throughout an ultimately terminal illness trajectory. While some organizations such as World Health Organization,[18] National Consensus Project (NCP),[19] and Center to Advance Palliative Care[20] all conceptualize palliative care as a philosophy of care and as such, palliative care interventions are provided to patients and families early in the course of a life-limiting illness in concert with therapies intended to prolong life. Other prominent organizations focus on advanced disease and end-of-life care. For example, the International Association of Hospice and Palliative Care[21] describes palliative care as limited to advanced disease (for heart failure, the patient must be refractory to all treatments) and provided by a specialty trained team of providers. Although they do suggest that the principles of palliative care can be applied earlier in a disease trajectory and by all health care providers who care for the patient. Another prominent organization, the American Academy of Hospice and Palliative Care Medicine's[22] also discusses palliative care as a care delivery service that needs a consultation or as hospice care. Thus, the conflicting conceptualizations of palliative care as a system of care delivery as opposed to a philosophy of care may influence the introduction of these much needed services prior to the terminal phase of a life-limiting disease, such as heart failure.

Aim of the Investigation

In this study we explored the meaning of palliative care in the context of heart failure from three perspectives: the scientific literature on palliative care in the context of heart failure, health care providers, and spousal caregivers of heart failure patients. The aim was to uncover possible sources of explicit and more implicit meaning that both facilitates and inhibits the introduction of this potentially valuable set of services for patients and families living through the course of advanced heart failure.

Methods

For the first inquiry, the scientific literature on palliative care in the context of heart failure, a search of the terms palliative care and heart failure was conducted on the electronic databases of PubMed (MEDLINE), Cumulative Index for Nursing and Allied Health Literature (CINAHL), and ProQuest Nursing and Allied Health. The second inquiry of health care providers' perspectives was investigated using both extant scientific literature on health care providers' perceptions of palliative care and data collected through three small group interviews with heart failure health care providers that was part of a larger study of wives of patients with heart failure (NIH/NINR; 1R15NR009976). Finally, the family caregivers' perspectives of palliative care were explored using data from two studies of spousal caregivers of patients with heart failure (NIH/NINR; 1R15NR009976 and AHA, Pennsylvania/Delaware Affiliate, Grant-in-Aid program).

Results

Scientific literature: heart failure and palliative care

An electronic search of PubMed, CINAHL, and ProQuest using the terms palliative care and heart failure, limited to 10 years (1998–2008) and English-language only resulted in a total of 211 unique articles being found. Eighty-five articles were eliminated because the focus was not heart failure and/or palliative care; 19 focused solely on the management of heart failure; 7 on heart failure experiences at end of life; 11 were health care providers' perceptions of palliative care; 44 used the term palliative care in concert with hospice care/end-of-life care (end-stage heart failure) and treatments; and 31 discussed symptom management at end of life, such as intravenous medications or surgical devices used for palliation. Only 14 articles were found that specifically focused on palliative care pre-end of life. Thus in the scientific literature for the past 10 years, only 14 articles related to palliative care and heart failure addressed the need for and provision of palliative care services prior to the terminal or end-of-life phase of heart failure. Table 1 presents the articles that discuss palliative care/interventions early in the disease process of heart failure.

Health care providers: meaning of palliative care

Scientific literature. Despite global definitions of palliative care and calls for palliative care for patients with heart failure, perceptions of palliative care by health care professionals vary. As seen in most of the scientific literature, palliative care is only equated with end-of-life/hospice care. A review of the 11 articles that focused on health care providers' perceptions and understanding of palliative care reinforced the confusion of the concept within the medical community. In addition to the perception of palliative care as care of the dying,[9,23–25] two issues were apparent: noncancer patients received less palliative care than cancer patients[26] and providers were unsure what to do with noncancer patients, such as those with heart failure.[23] The other articles focused on needs and issues surrounding provision of palliative care in general[2,24,27–29] and a lack of understanding of palliative care guidelines by primary care providers and cardiologists and the feeling that these services are in the realm of specialists.[23,24,30]

Heart failure team perceptions of palliative care. To add to this extant body of literature, three small group interviews were done with health care providers in varying roles on the heart failure team. A total of nine health care providers were interviewed; three heart failure physicians and six advanced practice/research nurses. As part of these interviews, the providers were asked to define the term palliative care and explain when palliative care interventions should be implemented.

Four of the nurses interviewed equated palliative care with end-of-life care or as "one step prior to hospice care." The following quotes exemplify this perspective: "When you're told there's not a lot more options and we're just going to try

Table 1. Articles that Refer to Palliative Care Pre-End of Life

Authors	*Title*	*Focus*
Cortis and Williams[33]	Palliative and supportive needs of older adults with heart failure	(UK): Understand older adults palliative and supportive needs (narratives) ($n = 10$), throughout course of disease
Gibb et al.[35]	Living with and dying from heart failure: The role of palliative care	General discussion of unmet needs of patients with heart failure, palliative care can improve quality of life for patients with incurable diseases, discussion of delivery issues in UK
Goodlin[36]	Palliative care for end-stage heart failure	Palliative care or supportive care throughout illness; description of palliative care, supportive care, and symptom management
Goodlin et al.[37]	Consensus statement: Palliative and supportive care in advanced heart failure	Consensus conference report about identification gaps and knowledge, supportive care throughout treatment
Hauptman and Havranek[38]	Integrating palliative care into heart failure care	Models of care for heart failure—palliative care early in disease, hospice- transition
Horne and Payne[10]	Removing the boundaries: Palliative care for patients with heart failure	Interviewed 20 heart failure patients—Experience of patients with HF and needs for palliative care, Palliative care for severe (not necessarily end of life)
Jones et al. and Gray[39]	Living and dying with congestive heart failure: Addressing the needs of older congestive heart failure patients	Commentary from UK on palliative care most effective from diagnosis to death
Leland[40]	Death and Dying: Management of patients with end-stage heart failure	Discussion of end-stage but symptom management discussed at all stages of the disease
Pantilat and Steime[8]	Palliative care for patients with heart failure	Timing and types palliative care interventions Starting early in disease
Quaglietti et al.[12]	Management of the patient with congestive heart failure using outpatient, home, and palliative care	Summary of management research for heart failure Palliative care both chronic and advanced heart failure
Selman et al.[41]	Modeling services to meet the palliative care needs of chronic heart failure patients and their families: Current practice in UK	Interviews with heath care providers in UK—need more coordination of palliative care with cardiology, and community nurses from outset
Stuart[42]	Palliative care and hospice in advanced heart failure	Discussion of principles of palliative care as person transitions to late-stage disease
Ward[43]	The need for palliative care in the management of heart failure	Needs with heart failure that would best be managed by palliative care Palliative care initiated early in course of the disease
Ward[44]	The quality of life in heart failure just talking about it will not make it better	Editorial: palliative care support chronic heart failure

to keep you comfortable with medicines or backing off on some of the more aggressive treatments" and "you've exhausted every opportunity for their care and there's nothing else to offer." Two of the nurses conceptualized palliative care more broadly. One said, "Support during a chronic illness that doesn't have a cure. . . . It's not hospice but it's additional support to help perhaps with anxiety," however when operationalized into practice, it became: "a bridge to hospice because generally when we use palliative care we are going to try to maintain that person in that quality of life as long as possible." Thus, although three of the nurses believed that palliative care should be implemented early in the course of a disease, actual implementation was discussed as part of end-of-life care or care given too late, so the next step was hospice.

The heart failure physicians clearly differentiated palliative care from hospice, with one physician saying, "Hospice is a small piece of a much larger umbrella that you may call palliative care." Although the term was defined as, "purely symptom relief and not the prolongation of life or improvement of organ function" and if something is "life extending therapy we don't view it quite as palliative," they operationalized interventions earlier in the disease trajectory, because the actual terminal prognosis was difficult to ascertain. One physician said, "You offer palliation to everyone and may even concentrate on it in lots of cases where death is not expected particularly soon." They also discussed offering patients and families the "last big thing we have" or the "last ditch" treatment, only to have issues resolve and the course of the illness and the treatment plan change.

For all the health care providers interviewed, one of the biggest concerns with introducing palliative care was the term being associated with pre-death care. So in many instances palliative care interventions were not introduced because it was felt "not necessary at this point." The other major reason was a concern that you were telling the patient that they were preterminal, one provider said, "A lot of people may not discuss it [palliative care] because you don't want to come in and be the one to give the impression that some one is gonna die."

In summary, although the term palliative care remained associated with end-of-life care and relief of symptoms, both nurses and physicians described interventions throughout the course of the illness that would be considered palliative care. For example, all the physicians had discussions about advance directives early in the course of the disease. The nurses also provided both financial and family counseling throughout the disease process.

Perceptions of palliative care among spouses of patients with heart failure

As a part of a two longitudinal investigations of the palliative care needs for heart failure patients and their family caregivers (Comprehensive Palliative Care: Spousal Caregivers of Heart Failure Patients; NIH/NINR; 1R15NR009976 and Investigation of palliative care needs of elderly heart failure patients and their spousal caregivers. AHA, Pennsylvania/Delaware Affiliate, Grant-in-Aid program), spousal caregivers were asked to define the term palliative care and once a definition was given to them, if and when these interventions would be acceptable. In both studies, spousal caregivers were individually interviewed monthly for minimally one year to follow the changing needs across their husband's or wife's illness trajectory. A total of 38 spousal caregivers (34 females and 4 males) from these two studies were included.

The majority of the spousal caregivers could not provide a definition for palliative care ($n = 26$). Statements such as "I've never heard of it" were very common. Other caregivers incorrectly defined palliative care ($n = 4$). One woman defined palliative care as "care of my husband that is done out of love." A male caregiver thought it was care provided by a good friend.

Several caregivers gave definitions of palliative care that equated it to end-of-life care or hospice ($n = 6$). In describing their perceptions of palliative care, these participants used statements such as, "end-of-life care," "terminal care like for people who had cancer," and "comfort care." Participants who offered this type of definition included a registered nurse, a woman working at a medical center, and several people living near a hospital with a palliative care/hospice inpatient unit. Only two caregivers defined palliative care broadly and acknowledged its usefulness prior to end of life. One woman who worked in a hospital stated that palliative care was similar to hospice, but useful for "a chronic illness that will not really get better. It is not necessarily a timed thing." Another caregiver who worked with patients with human immunodeficiency virus (HIV) said that "It's more like case management. A person could be terminally ill, but not near the end." For these caregivers, prior exposure to palliative care increased and broadened their understanding of the concept.

After a definition of palliative care was provided, all caregivers thought that the services were valuable and would be acceptable. However, the timing of when these services were needed or would be acceptable was split pretty evenly among the caregivers. Some felt these interventions should come early in the disease trajectory. One woman said, "When all of this first started and we were at (the hospital) most definitely at that point in time . . . I felt so alone . . . there was nobody to talk to. That would have been something that would have been fantastic." Others felt that they presently could use many of these services. One female caregiver said, "It should be at this point in his life because it would give him a better quality of life while he still has it." Another caregiver related that it would help her, but that her husband would probably not be receptive to it. While some caregivers, whose spouses were presently stable, thought that if the condition worsened, then they would appreciate these services.

In summary, these spousal caregivers were not familiar with the term palliative care. The few participants who had some prior knowledge of palliative care either provided a broad definition or were likely to associate it with end-of-life or hospice care. Some caregivers lived near a hospital with a palliative care unit specifically meant for end-of-life care. Other participants worked in health care or had a family member who received hospice care.

Discussion

Although leading health care organizations provide broad conceptualizations of palliative care, there remains confusion in the medical community and the scientific literature as to the meaning of this term and the provision of these services. Thus, the implied meaning that palliative care equates to end-of-life or hospice care, may be a significant factor in the lack of services provided to patients and families with heart failure. The majority of scientific literature and health care providers use the term as terminal care or interventions needed during the advanced stages of heart failure. As a result of palliative care being associated with a terminal diagnosis, health care providers may be reluctant to discuss palliative care with heart failure patients early in the disease trajectory.[8] However, as seen with the spouses in our research, many lay people have not heard of the term and all would be receptive to an offer of palliative care interventions at some point during the disease trajectory.

One issue that may also lead to the confusion with the introduction of palliative care is that, in many instances, it is associated with an end-of-life service. Thus, instead of conceptualizing palliative care more broadly as a philosophy or approach to care where a set of interventions could introduced at various times across a disease trajectory, it is considered a service that requires a specific referral.[31,32] This view is found throughout the scientific literature; mainly focused on inpatient referrals in the United States and outpatient care in the United Kingdom.[2,24,26,27,33] A second issue is the lack of understanding of the wide range of supportive interventions subsumed under the umbrella of palliative care. This type of supportive care encompasses many interventions that are routinely done by health care providers, but not identified as such, for example, the discussion of advance directives or family counseling. Another issue relates to whose responsibility it is to provide this type of care and who gets reimbursed for these services. There is no consensus in the scientific literature related to this; some feeling that these interventions are in the realm of nursing,[23] while others, the general practitioner[2] or cardiologist,[32,34] and still others an end-of-life specialist.[28,32]

Through the examination of the scientific literature, the meaning of palliative care with heart failure and health care providers' perspectives of palliative care in both the extant literature and through small group interview, it is clear that the implicit meaning of palliative care as being terminal care influences it use with heart failure patients and caregivers. Thus there continues to be many issues surrounding the provision of palliative care interventions to patients and families who do not fit the typical "cancer" model. One thing that is also evident throughout the scientific literature is that patients with heart failure are not receiving palliative care interventions, even at the end of life. Comprehensive palliative care services have the potential to help patients and their caregivers in dealing with the challenges of living with heart failure thus are appropriate throughout the illness. A reconceptualization of palliative care as a philosophy of supportive care interventions may need to be done before these services are routinely provided to heart failure patients and those with other life-limiting diseases.

Author Disclosure Statement

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