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EDUCATIONAL CORNER

VOICES IN CARDIOLOGY

The Importance of Palliative Care in Cardiology

Differences Between Countries

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A 75-year-old man with dilated cardiomyopathy status post-implantable cardioverter-defibrillator (ICD) presented with progressive dyspnea and ascites refractory to medical therapy. He underwent paracentesis for symptom relief. The patient was discharged to a local rehabilitation facility and continued to receive palliative paracentesis. However, given the burden of these repeated paracenteses, the patient requested a more permanent solution. Because this was in line with his stated wishes for symptomatic relief, the decision was made to place a drain so that future procedures would be less burdensome. En route to the interventional radiology laboratory for the procedure, however, he suffered multiple ICD shocks and passed away. Neither during his hospital stay nor during multiple outpatient appointments related to his cardiac disease were discussions about his goals of care or the concept of deactivating the shocking function of the ICD introduced to him.

As the population ages and medicine continues to advance, patients are living longer with multiple comorbidities. This is especially true for patients with advanced heart failure who, due to the recent advances in medications and technologies, are living longer than ever before (1). Longevity in heart failure is often associated with more hospitalizations and increased symptom burden, which can become increasingly difficult to manage. While cardiologists are outstanding clinicians who excel at managing acute heart failure exacerbation, patients with this disease are complex and often need a holistic and multidisciplinary approach to manage their physical and psychological symptoms, ensure they have disease understanding, and are receiving treatments that are appropriate based on their goals and values. The early integration of palliative care into the care of cardiac patients significantly improves the patient's quality of life and patient and caregiver satisfaction and reduces symptoms (2). Palliative care is specialized medical care for people with serious illness. The goal is to improve the quality of life for patients and their families. Palliative care can be delivered to patients of any age and at any stage of their illness. It is offered simultaneously with efforts to cure disease and prolong life. While the robust evidence base for palliative care in oncology has led to it becoming the standard of care for patients with cancer, the integration of palliative care in cardiology is not as well established. In 2016, the American Heart Association endorsed the early integration of palliative care into the care of all patients with advanced heart failure. However, these recommendations have not been integrated into routine practice. Cardiologists could benefit from greater adoption of basic palliative care skills, particularly as they relate to communication regarding advance care planning, clarifying disease understanding, and elucidating patients' goals of care, to use during their routine practice to help patients understand their disease status, prognosis, and available treatment options and to improve decision-making. This paper discusses the importance of better integration of palliative care into the field of cardiology.

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PREDICTING DISEASE TRAJECTORY: THE CRYSTAL BALL IS MURKY

It can often be difficult to predict prognosis for patients with heart failure. While they can seem stable enough for "follow-up in 1 year" at the end of a routine office visit, they may be admitted to the hospital the next week with a heart failure exacerbation, and in other cases, the exact opposite may be true. At times, patients may be critically ill in the intensive care unit receiving advanced life support, and it seems unlikely they will survive, yet a few months later they are seen in the office for routine follow-up. Heart failure patients have a variable disease course, and they experience periods of relapse and remission (3). In some patients with end-stage heart failure, the progressive worsening of their symptoms can lead to an inability to perform activities of daily living, social isolation, and to increased dependence on caregivers, family, and financial resources. Such patients would benefit from having their cardiologists engage in "primary palliative care" by communicating with them to clarify their disease understanding, educating them about the course of the disease, and begin engaging in conversations pertinent to advance care planning and goals of care (4). These conversations often begin with simple open-ended questions such as, "Tell me what you understand about your heart disease" or "Talk to me about what is important to you in terms of your quality of life so we can better determine what treatments are appropriate for you now and in the future." As patients' disease progresses, for example, as they approach stages C and D, clinicians may consider referral to specialty-level palliative care to assist with more complex decision-making (4).

BARRIERS TO PALLIATIVE CARE

Initiating conversations about goals of care and treatment decisions can be difficult, especially since these conversations are often long, complex, and have a significant emotional component to them on the part of the patient and the family. This complexity is compounded by the fact that clinicians may feel uncomfortable with these conversations due to inadequate training, time constraints, and challenges predicting prognosis. There is also confusion between specialty palliative care service and hospice. Specialty palliative care service is for patients at any stage of illness and is delivered at the same time as efforts to cure disease or prolong life, whereas hospice is for patients near the end of life who wish to forgo therapies aimed at prolonging life and focus only on comfort. Some patients may deem palliative care as withdrawal of treatment or being synonymous with the fact that they are at the end of life.

The sum of all these barriers can lead to the current practice of specialty palliative care services being underused in cardiac patients and typically erroneously relegated to end-of-life care. However, current guidelines advocate early involvement of palliative care in heart failure patients to improve quality of life, reduce hospital readmission, and help manage chronic symptoms. This includes integration of palliative care into the heart failure clinic and the availability of specialty-level palliative care in the hospital and the community. However, many of these problems can be avoided if the cardiologist first introduces concepts such as understanding of the disease and goals of care early in the disease process and then, as the disease progresses, introduces speciality-level palliative care services to patients and their families.

ABBREVIATIONS AND ACRONYMS

ICD = implantable cardioverter-defibrillator

PRIMUM NON NOCERE

Cardiologists often feel the need to continue to offer additional clinical therapies without determining if the therapies are in line with patients' goals and wishes for their health care. Sir William Osler said, "the good physician treats the disease; the great physician treats the patient who has the disease." A great cardiologist understands patients in the context of their illness but also their goals and values. The case scenario is adapted from a patient who died an uncomfortable death en route to the interventional radiology laboratory, thus clearly demonstrating the importance of introducing palliative care earlier into the disease course to avoid undue harm. If goals of care conversations had happened earlier, both by the patient's primary cardiologist and through introduction to specialty-level palliative care, he might have passed away in a more dignified and comfortable manner with his family by his side. There had been multiple missed opportunities to discuss his disease prognosis, limitations of the procedure, goals of care, code status, and role of the ICD. Ideally, each one of these elements would be addressed at different times in the office and in the hospital to allow the patient and his family to understand the seriousness of his illness over time. As the patient became more debilitated and frail, specialty palliative care consultation could have been helpful for his refractory symptoms and to aid in complex decisions such as device deactivation and end-of-life care.

TABLE 1 Useful Palliative Care Practices for Cardiologists

Prognostication	Formulate an individualized estimate for patients to help them understand their disease status and prognosis while acknowledging the unpredictable nature of the disease; begin such conversations by asking if the patient wants this information to ensure the level of information delivered is in line with their desire for the knowledge.
Communication	Engage with patients and their families in shared decision-making by using open-ended question to explore patient understanding, desired outcomes, and how they define optimal outcomes.
Advanced care planning	Discuss goals of care and appropriate treatments based on those goals early in the disease process and re-evaluate these goals over time as the patient's disease progresses.
Palliative care	Consider referral to specialty-level palliative care when patients have refractory symptoms or when barriers to communication and advance care planning are encountered.
Palliation not withdrawal	Effectively communicate with patients and their families that palliative care provides holistic person-centered care aimed at improving quality of life. It is not withdrawal of treatment and is not the same as hospice.
Symptom management	Recognize and treat common heart failure symptoms and sources of distress including dyspnea, pain, fatigue, anxiety, insomnia, and depression.
Grief and bereavement	Involve family members and caregivers in all plans of care to help them cope with the patient's illness and reduce their risk of complicated bereavement.
Spiritual aspect	Integrate spiritual care for patients to improve their quality of life and provide holistic care of the patient and family.
Device deactivation	Discuss the option of device deactivation with patients with advanced illness as appropriate based on their goals and wishes for their health care.
Legal and ethical perspective	Understand and explain to patients and families that device deactivation is neither assisted suicide nor euthanasia. It is legally and ethically permissible.

DEVICE DEACTIVATION: A COMPLEX CONVERSATION

As indications for device therapy continue to expand, more patients are receiving ICDs. Recently, Trussler et al. (5) showed that up to 20% of patients with ICD receive painful shocks in the last month of life, which is associated with poor quality of life and causes significant distress to patients and families. Ultimately, all patients will reach the end of their lives, but cardiologists rarely discuss the option of device deactivation with patients and families, even among patients with "Do Not Resuscitate" orders. For several reasons, many cardiologists report uneasiness with conversations about device deactivation (6). On the other hand, patients perceive a dependence on their ICD and think device deactivation means suicide. There is consensus that deactivating the shocking function of the ICD in dying patients is ethically and legally permissible (6). Training programs should incorporate teaching about the importance of discussions on device deactivation to improve communication skills and promote a shared decision-making process.

PALLIATIVE CARE TRAINING IN CARDIOLOGY

Most cardiology trainees receive little to no teaching of palliative care concepts such as assessing disease understanding, evaluating patients' goals for their health care, and establishing treatments based on those goals (7). In a recent survey of 18 academic cardiology fellowship programs in the United States, more than 96% of cardiology fellows and faculty agreed that palliative care training is important for cardiologists, yet no palliative care training curriculum exists for cardiology fellows (6). The results of this survey highlight an urgent need for formal training in palliative care principles, which include communication skills, symptom management, care for patients at the end of life, and bereavement. Trainees should also receive formal training in appropriate indications for specialty-level palliative care consultation, in learning how to engage in a shared decision-making process, and in becoming aware of the psychosocial, spiritual, and cultural aspects of care for patients with advanced disease. Palliative care practices that cardiologists could integrate into their daily practice are presented in Table 1.

Overall, the use of palliative care in cardiology is still in its infancy. Two authors of this paper, Dr. Yakup Kilic, a medical trainee in cardiology in the United Kingdom, and Dr. Aiman Smer, an early-career cardiologist in the United States, agree that cardiologists across the Atlantic encounter the same challenges as mentioned above and receive limited training in palliative care. However, there is growing interest in both health care systems to better integrate palliative care in the field of cardiology and to implement palliative care in heart failure clinics.

The complex and unpredictable nature of advanced heart failure poses a unique opportunity for cardiologists everywhere to better integrate palliative care principles and practices into their daily care of patients, to implement cultural change, and to ensure the highest quality of care for patients and their families.

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