Clinical Update

News About Caring for People Through the Stages of Serious Illness

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Helping Lila Through the Stages of Advanced Cardiac Illness

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Lila,* 92, who had end-stage congestive heart failure (CHF), was receiving rehab care at a nursing home after multiple hospitalizations for severe dyspnea, angina and anxiety. Despite the staff's best efforts to help improve Lila's cardiac symptoms and anxiety, she continued to struggle and became weaker.

Lila's family did not understand how advanced her heart failure was, and they were surprised when she died after six weeks in rehab care, rather than becoming well enough to go home. Although her condition was clearly terminal, crucial conversations did not occur between Lila's doctor and her family, who were left wondering if more could have been done for Lila in her final weeks.

End-stage heart failure affects five million people in the United States. It is the most frequent cause of hospital admission and readmission. Many of these patients have other co-morbid conditions, such as pulmonary disease, renal disease or diabetes. In the elderly with end-stage heart failure, the one-year mortality rate is greater than 60 percent.[1]

Do you know someone whose cardiac disease has led to repeated hospitalizations or emergency room visits? Or someone who is experiencing increasing edema, shortness of breath, fatigue or general malaise? Patients with these symptoms need all the help that is available to live the best life possible through the stages of advanced cardiac illness.

For some patients, hospice services will help manage their comfort and prepare them and their family emotionally for what to expect as their illness progresses. For patients who are seriously ill but not clearly in the six-month prognosis window for hospice, Agrace's palliative care services may be a valuable benefit; they include in-home palliative care consultations with follow-up visits, and Care Navigation, an in-home evaluation with ongoing telephone support and a monthly home visit from a palliative care RN. For more details, please ask your Agrace liaison or visit agrace.org/palliativecare.

Palliative care seeks to improve a patient's quality of life at *any* stage of a serious illness. This "whole-person" supportive care supplements a patient's medical care by also assessing and addressing the emotional stressors, spiritual concerns and social implications the patient is experiencing. **Palliative care can be offered at the same time as life-prolonging therapy: Patients do not have to choose between curative care and palliative care.** Both the American College of Cardiology and the American Heart Association now recommend ongoing discussions with patients and their families about palliative care.

Indicators for palliative care: It can be difficult to know which cardiac patients may benefit the most from palliative care. A 2012 study by Thoonsen et al.[2] identified seven indicators that should trigger a palliative care intervention:

1. The patient has severe limitations and experiences symptoms even while at rest; mostly bedbound patients (NYHAa IV).
2. There are frequent hospital admissions (>3 per year).

**Lila's story is not the experience of a specific patient, but an illustration of patient experiences Agrace's staff has commonly encountered.*

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Helping Through the Stages of Advanced Cardiac Illness, continued

3. The patient has frequent exacerbations of severe heart failure (>3 per year).
4. The patient is moderately disabled, dependent, and requires considerable assistance and frequent care (Karnofsky score ≤ 50%).
5. The patient's weight increases and fails to respond to increased dose of diuretics.
6. A general deterioration of the clinical situation (edema, orthopnea, nocturia, dyspnea).
7. The patient mentions end of life approaching.

Hospice criteria for cardiac patients: When evaluating patients with cardiac disease, hospices use the NYHA guidelines. Typically this includes Class IV symptoms with an ejection fraction of less than 20 percent. We also look for optimal use of diuretics, ACE inhibitors, vasodilators, beta-blockers, aldosterone inhibitors and device therapies. Patients often have severe, persistent symptoms in spite of the therapy or reasons for not being able to tolerate the therapy, such as hypotension or renal disease.

Additional factors may also contribute to a six-month-or-less prognosis, such as symptomatic ventricular arrhythmias, history of cardiac arrest with resuscitation, unexplained syncope and/or an embolic CVA with a cardiac origin.

Having the Conversation

When a patient's prognosis makes palliative care or hospice a viable option, it can be very hard for patients and families to hear the words. But having these difficult conversations gives them the ability to make well-informed choices.

Agrace physicians and nurses are often asked for advice when clinicians have difficulty finding the right words to discuss palliative care or hospice. Here are some suggestions for talking with patients with advanced heart disease:

"Lila, I'd like to talk with you about your heart condition. Despite our best efforts, your heart disease is progressing. I anticipate that you may become weaker and could experience more symptoms. I'd like to refer you to [a palliative care practitioner/hospice services]. [Palliative care/hospice] provides additional support to patients and families with advancing illness …"

"Lila, you've told me that it's important for you to understand your health condition so you can make choices that fit your values and preferences. Based on my assessment today, I can see that your heart failure is worsening. You are reaching a point when more aggressive treatment, such as hospitalization, may no longer be beneficial. At this time, you might benefit from additional support that can be provided by [palliative care/hospice care]. If you are interested in learning more, I'd like to make a referral today so you can get some extra assistance soon …"

Agrace's services can complement your patients' medical care and lead to a better quality of life during a chronic or advanced illness. To discuss eligibility for services or refer a patient for a palliative care consultation, Care Navigation or hospice, please call (800) 930-2770.

[1] Salpeter S, Luo E, Malter D, Stuart B. Systematic review of noncancer presentations with a median survival of 6 months or less. American Journal of Medicine [serial online]. May 2012;125(5):512.e1-512.e16. Available from: CINAHL Plus with Full Text, Ipswich, MA.

[2] Thoonsen B, Engels Y, Vissers K, et al. Early identification of palliative care patients in general practice: development of RADboud indicators for PAlliative Care Needs (RADPAC). British Journal of General Practice [serial online]. September 2012;62(602):625-631. Available from: CINAHL Plus with Full Text, Ipswich, MA.

New Resource Offered

Agrace offers clinicians a convenient, pocket-sized reference, "Clinical Indicators for Palliative Care & Guidelines for Hospice Eligibility." The guidelines cover 13 common hospice diagnoses. Please ask your Agrace liaison for one, or email a request to Natasha Weberg, director of outreach, at natasha.weberg@agrace.org.