

EDITOR'S PAGE



Dying With Dignity and Heart Failure

A Lesson From Barbara Bush

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We recently witnessed the death of Barbara Bush at 92 years of age in the presence of her family at home under comfort care and palliative measures. She had been diagnosed with chronic obstructive pulmonary disease (COPD) and heart failure for many years, and in the past year, she had been hospitalized several times. Given her history, age, and the dangerous intersection of COPD and heart failure, it was clear that she had a very high risk for recurrent hospitalizations and death. In the end, she made the courageous decision with her family to die with quality of life, not quantity of life. She took her care home and focused on relieving symptoms and providing care for herself and family needs. In her last days of life, it was stated that she was enjoying the company of her husband, children, and grandchildren, as well as sharing stories, drinking bourbon, and providing advice as she often did. She died peacefully on April 17th, 2018, in the presence of her extended family and beloved husband.

This event reminds us of the importance of caring for the complete patient, and understanding patient and family needs, as well as quality of life as a priority over quantity of life in this type of circumstance. In the last 6 months in the life of a patient with heart failure, an enormous amount of resources and dollars are spent providing care that may have limited opportunities for improving long-term outcomes. Palliative care and hospice are often not instituted early in the last 6 months of life, and many times not at all.

Two recent studies, one published in *JACC* and one in *JAMA Cardiology*, have offered important insights through the randomized controlled clinical trials of interventions of providing palliative care by a team of health care providers (1,2). In the PAL-HF (Palliative Care in Heart Failure) study, advanced heart failure patients with an anticipated 6-month

50% mortality showed significant improvement in quality of life with a reduction in depressive symptoms without an extension of life in the palliative care intervention arm. In this palliative care strategy, they focused on overall well-being, relief of symptoms, and reducing stress and anxiety of the illness, as well as caretaker participation. Patients had an improvement in the Kansas City Cardiomyopathy Questionnaire quality-of-life scale that was measurably much larger than that seen with most pharmacological and device therapies. In addition, depressive symptoms and anxiety were significantly reduced with the palliative care strategy versus usual care. It is this emerging body of evidence that needs to be taught to our colleagues and trainees, who could then begin to take a more thoughtful approach to heart failure in those patients with multiple comorbidities and advanced age to provide an environment of comfort care that best meets the needs of the family and patient.

In addition, it is important to address the fear of the patient and the family in the process. The greatest fear that the patients have is suffering: the suffering of breathlessness and pain, both exacerbated in a patient with COPD and heart failure (3). By use of a tool kit of options that could include medicines for symptom relief including oxygen, morphine, anxiolytics, and antidepressants, one can overcome these fears and provide a comfortable means for death. Additionally, it is extremely important that they have the social support of the extended family and friends during this time. One knows that social isolation and the lack of social support can increase depressive symptoms and anxiety, and worsen the overall state of a patient. Therefore, engaging the extended family through this process is extremely important.

To this end, Barbara Bush provided a very good lesson for heart failure care providers, a lesson that we should not forget in our daily quest to improve the quality and quantity of life of the patients who we serve.

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