Heart Failure Patients Need More Than Heart Failure Care*

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As providers we often mentally identify our patients based on the most important condition we manage during clinical interactions, hence, for example, the term heart failure patient. In the coronary care unit we group patients into typical categories, such as ischemic, heart failure, or arrhythmia admissions. Such simplification is natural and helpful in remembering the correct patient and communicating with other providers. The coding of diagnoses with each clinic visit reinforces the association of the patient with 1 or perhaps a few conditions depending on how impatient we are with our electronic medical record. Although this is a useful way to track patients for population health this labeling overestimates the importance of the condition to the individual.

In this issue of JACC: Heart Failure, Joyce et al. (1) show how “heart failure patients” often do not think heart failure is their main problem. The investigators from Brigham and Women’s Hospital examined the contribution of heart failure to quality of life among patients in their heart failure clinic. Clearly heart failure is an important medical condition for these patients given that they chose to attend a clinic specializing in heart failure at a major tertiary referral center. However, only one-half of the patients with heart failure said their quality of life was primarily limited by heart failure symptoms. In the other half noncardiac and nonmedical problems were equally or more important.

Although their results should be generalizable to other heart failure clinics, the findings may be even more striking for patients followed only in primary care. The mean age of the patients in the current study was 56 years and primary care patients are likely to be 15 years older on average. Those patients with heart failure who are not referred to a heart failure clinic have more comorbidities and less severe heart failure. It is reasonable to assume that heart failure is usually not the most important issue impacting their quality of life.

Still, for one-half the patients in the Joyce study, heart failure was the major contributor to poor quality of life. We know that heart failure-specific health status and overall quality of life are often markedly depressed with heart failure. Two common measures of overall quality of life are the Short Form Questionnaire (e.g., SF-36) and a utility measurement. The latter measures the patient preference for quality versus length of life. In a study of similarly aged patients, the SF-36 physical component score was 34 (normal population mean, 84) and the mental health component score was 49 (normal population mean, 75) (2,3). The utility was 0.77, indicating patients would be willing to give up 23% of their remaining lifetime if they could live it in restored health. Clearly those with heart failure are suffering, and for many, the symptoms of heart failure are the reason. A recent study compared overall quality of life with a heart failure-specific measure and found that heart failure symptoms were significantly associated with overall quality of life using a utility, but so were other factors including age, gender, and the Charlson score for comorbidities (4). Without an understanding of the importance of other individual comorbidities we often attribute the entire reduction in quality of life to heart failure.

Economic forecasts may also ignore comorbid conditions. Many analyses of the “impact” of heart failure...
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Heart failure care attribute all medical costs to heart failure for patients with a diagnosis of heart failure. When analyzed in a way that does not allow double counting, a study by the American Heart Association estimated that direct medical costs attributable to heart failure will be $51 billion per year by 2030 (5). Although a substantial sum, the total direct medical costs for these patients will be 3-fold higher ($160 billion). One can see that estimated cost savings will be wildly unrealistic if we simply attribute all costs to a single condition.

Similarly, overattribution leads to inaccurate predictions on how effective heart failure interventions will be in improving quality of life. Clinical trials have focused on disease-specific measures of heart failure (e.g., Kansas City Cardiomyopathy Questionnaire or the Minnesota Living With Heart Failure Questionnaire) in part because of limited ability to detect an effect of an intervention using general measures of quality of life. Joyce et al. (1) note that their finding of the lack of importance of heart failure to many patients “highlights the futility of focusing on HF-specific therapies alone in modifying quality of life in heart failure patients.” Many hospital administrators were surprised and disappointed to find that optimization of inpatient heart failure did not reduce readmissions and any associated penalty imposed by the Center for Medicare and Medicaid Services. If judged by the reason for readmission, the main problem for the patient discharged with heart failure is some other condition for 2 in 3 patients.

How should we respond to these results? First, researchers should always include an overall measure of health status, ideally a utility measure that estimates the patient’s preference for quality of life in addition to a heart failure-specific measure. Heart failure-specific questionnaires are important because they are more sensitive to clinical change and useful in detecting an effect of an intervention’s symptoms than overall quality of life questionnaires. However, in choosing interventions that have adequate value we need a measure of overall quality of life that can be compared across diseases and conditions. For the clinician a small step is to describe patients as having heart failure rather than labeling them a heart failure patient.

More importantly, the findings from Joyce et al. (1) argue that a comprehensive, holistic approach is needed. Ideally this is by whomever is providing primary care to the patient with heart failure. I would argue it is beyond the expertise of most heart failure clinics to manage the varied noncardiovascular complaints that are the greatest determinates of quality of life for different patients. This is even a challenge for primary care physicians practicing in a medical home.

One strategy is to consider “palliative” care for all patients with significant symptoms and multiple comorbidities regardless of prognosis. Traditionally, palliative care has been used for those at the end-of-life when prolongation of survival is no longer a goal. Its use in heart failure has been minimal for many reasons, including the difficulty in predicting end-of-life, and the fact that many life-prolonging therapies also improve symptoms and prevent deterioration (e.g., angiotensin-converting enzyme inhibitors, beta-blockers, mineralocorticoid antagonists, and cardiac resynchronization therapy). Withdrawal of these therapies usually worsens quality of life so the typical approach used in cancer of removing life-prolonging therapies does not make sense in heart failure. However, palliative care can address such common issues as pain and insomnia. Palliative care providers also focus on nonmedical conditions including spiritual, psychological, and social issues (6).

A recent randomized trial of palliative care consultation for patients with heart failure is illustrative (7). A cohort of hospitalized patients (but not in the intensive care unit, considered a transplant candidate, or treated with a left ventricular assist device) were randomized to receive consultation by palliative or usual care. Overall symptom burden, including those of depression and heart failure, improved significantly at 1 month among patients randomized to palliative care consultation.

Together the medical home and the heart failure clinic should take advantage of the skills of palliative care providers, creating a partnership that focuses simultaneously on improving length and quality of life (8). Through such a comprehensive approach to the patient with heart failure we will provide the highest-quality care.
REFERENCES


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