Editors

A Time to be Born and a Time to Die

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“‘I wanted a perfect ending. Now I’ve learned, the hard way, that some poems don’t rhyme, and some stories don’t have a clear beginning, middle, and end. Life is about not knowing, having to change, taking the moment and making the best of it, without knowing what’s going to happen next. Delicious ambiguity.’”

—Gilda Radner
US actress and comedienne (1946–1989)

What would you do if you knew you had 6 months to live? How would you choose to spend your time? Would you be willing to try an experimental and risky therapy that might decrease your quality but increase your quantity of life? What would you do if you knew that your patient had 6 months to live despite current clinical stability? Would you tell him? Would you be more or less “aggressive” with treatment options?

Physicians are often faced with life-or-death situations. In the abstract, we can conceptualize and rationalize biology, but the ability to convert our understanding of the natural course of a disease to a useful, sensitive, and realistic conversation with a patient and his or her family is something with which few are comfortable. This is especially true when the patient is awake, alert, and ambulatory. The word “prognosis” is derived from Greek, defined as “a forecast of the probable course or outcome of a disease.” Clinicians recognize that in most chronic illnesses, the prognosis is, at best, a guess but that ultimately death is inevitable. However, it is the time course, manner of death, and quality of life along the way that our patients most want to know. Physicians fear that delivering the news of a grave prognosis will send the patient into despair and rob them of any hope. Many clinicians still see death as professional failure and therefore are unwilling to face or are uncomfortable confronting the truth. Our personal discomfort discussing death and dying, combined with our perception of what patients want and do not want to hear, often prevents us from even considering the overall prognosis.

Defining prognosis for patients with chronic heart failure has become one of our greatest challenges. Over the past 20 years, heart failure has shifted from an acute disease managed primarily in the hospital that typically and rapidly led to death to one of the most common chronic illnesses in the world. In the past 2 decades, strategies for the management of heart failure have changed the natural history of the disease. Many patients are now able to enjoy reasonably functional lives for years, even in the setting of severe left ventricular dysfunction. The specter of sudden death has been substantially mitigated by implantable defibrillators. Nevertheless, despite advances in neurohormonal blockade, devices, and management of comorbidities, the mortality from heart failure remains unacceptably high. For men <65 years of age, 80% will die within 8 years, and 70% of women <65 years of age will die within 8 years.2

Heart failure management teams currently spend most of their time implementing the complex, guideline-directed therapies while encouraging patients to learn the tools of self-management. Successful implementation of a heart failure regimen depends in part on the team’s cheerleading, focusing on the promise of each therapy, device, and dose adjustment. This enthusiasm is contagious to our patients and helps them make significant lifestyle changes; our implicit, hopeful message is that if patients can merely be compliant with our instructions, everything will be fine. There is often little time or room in this environment to discuss the grim reality of impending death.

Objective evidence is now accumulating that clinicians do not estimate the risk of morbidity or mortality accurately in their heart failure patients. Yamokoski et al1 evaluated the predictive accuracy of physicians and nurses in estimating the risk of rehospitalization and death for patients with severe advanced heart failure enrolled in the Evaluation Study of Congestive Heart Failure and Pulmonary Artery Catheterization Effectiveness (ESCAPE) trial. They found that heart failure nurses were better able to predict mortality than physicians and that nurse estimations of mortality added significantly to a derived prognostic model. Physician estimations did not. It was hypothesized that the nurses were more attentive to the psychosocial characteristics of their patients and that these issues may be driving heart failure outcomes. Ironically, neither nurses nor physicians were very good at predicting rehospitalizations in this population of patients.

Patients are even less able to conceptualize their own risk of mortality or to understand the potential benefits of therapies. In a study by Weintraub et al,4 patients in 2 programs were asked to estimate the impact of an implantable defibrillator. Patients estimated that an implantable defibrillator would be life-saving in at least 50 of every 100 patients, whereas clinical trials suggest that ≈7 patients would be...
TABLE 1. Potential Benefits of Using Prognostic Models for Heart Failure

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<th>Benefit</th>
<th>Description</th>
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<td>Allows patients and families to have a realistic expectation of the prognosis</td>
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<td>Allows appropriate allocation of resources, including transplantation, mechanical circulatory assist devices, and implantable defibrillators</td>
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<tr>
<td>Allows selection of therapies most likely to positively affect the quality and quantity of life</td>
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<tr>
<td>Promotes open, honest communication between clinicians, patients, and their families to define the goals of therapy</td>
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The predictive model incorporates many clinical features and thus should provide a more accurate and robust prediction. Understanding mode of death for heart failure patients is important because it is closely linked to quality of life. Dying suddenly for some patients with very advanced heart failure may be their preference when contrasted against a slower and more uncomfortable pump failure death. Models that enable clinicians and patients to predict mode of death should help encourage discussion about preferences. In addition, they should promote a more rational approach to selecting therapies, including deactivating defibrillators and initiating hospice care.

Applying predictive models to an individual patient is not always straightforward (Table 2). The causes of heart failure are heterogeneous, and selecting a model derived from a different population of patients can be unhelpful or misleading. Models derived solely from men, or 1 race, or 1 origin of heart failure may perform well in these groups but may not be predictive in other groups. In addition, certain models have been derived specifically for acute decompensated heart failure, whereas others focus on ambulatory outpatients. The presence and severity of comorbidities also vary widely among the models. For this reason, it is critical that any predictive model be transparent about its derivation and be validated in several groups so that its performance can be objectively evaluated.

In general, predictive models assume that the patient will be compliant with therapies and lifestyle changes. Incorporating patient-specific variables like compliance, attitudes, and preferences into a predictive model is nearly impossible, and it is probably for these reasons that the nurses in the Yamokoski et al trial were able to improve the performance of the predictive model. In a sense, they knew the patient as an individual and could modify the model. This approach of combining a statistical, clinical, predictive model with the impressions of the patients’ clinician will ultimately be the most useful approach. The risk model scores should supplement but not supplant the clinician’s assessment and expertise.

The treatment of heart failure is constantly in flux, and new therapies and devices are continually being introduced. Risk models need to reflect these changes and must be rapidly adaptable so that clinicians and patients can understand the potential impact of a new intervention. In addition, heart failure as a disease changes over time. This makes 1 static model prediction risky. For example, a patient with moderate heart failure presents with atrial fibrillation that causes significant hemodynamic compromise. Her creatinine is elevated, and she is New York Heart Association class IV on...
presentation. An assessment of her status on admission may yield a poor prognosis, but with rate control or cardioversion, her clinical situation may improve. A recalculation using updated clinical variables may lead to a more favorable prognosis. Alternatively, an ideal model should incorporate the prognostic impact of both the occurrence of atrial fibrillation and the response to treatment. This single scenario illustrates the importance of clinical stability and aggressive use of guideline-mandated therapies before the prognostic model is applied.

Serial evaluations with a predictive model may be the most useful in updating prognosis and may yield a better overall assessment of risk. Likewise, it appeals to our practical sense of how these models should be used, eg, to evolve a prognosis as the patient’s disease unfolds. Although for most models serial assessments have not been validated, serial assessments, combined with the personal characteristics and preferences of the patient, may help the clinician, patient, and family come to terms with a poor prognosis. In this way, the model serves as a catalyst to the process of discussing and planning for the future, including a new therapeutic intervention or hospice.

The field of predictive modeling is relatively new, and clinicians have not yet embraced this new technology. In addition, the vast majority of physicians have not had the opportunity to observe the predictive accuracy of the risk models developed to date. Future efforts need to focus on making risk profiling in heart failure as common as those used in acute coronary syndromes or cancer. In this way, clinicians will better understand the risk characteristics of patients in published trials and may be better able to select appropriate patients for new therapies. In addition, the models themselves can be further refined.

We propose that the development, validation, and maintenance of prognostic models for heart failure be a priority. They should be incorporated prospectively into every future clinical trial and validated in community-based populations. Moreover, the impact of serial assessments on the overall performance of the models should be validated. We recognize that the use of a robust prognostic model should not replace the judgment of the team of multidisciplinary specialists caring for the heart failure patient but rather should supplement it. By systematically applying the appropriate models, the team will have an objective tool so that discussions about appropriateness of treatments and patient preferences can be initiated. All members of the team need to feel comfortable discussing prognosis and allowing patients and families to select therapies using realistic risk-benefit calculations. Finally, the team needs to recognize that serial assessments and discussions may need to be made over time as treatments, the disease state, and preferences evolve. After all, as the beloved and mourned comedienne Gilda Radner became famous for saying, “It’s always something.”

Disclosures
None.

References

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