It is human nature to wish knowledge of the future. This fact is no more apparent than when one considers issues of life goals, priorities, and of mortality. Thus, it should not come as a surprise to us when our patients with chronic heart failure ask what their prospects for future life may be. As clinicians and patient advocates, we are obliged to provide the best information and advice that we can so that our patients are able to make decisions regarding their future. To simplify our duties, many researchers have provided algorithms to predict adverse outcomes, such as mortality. We have been treated to several risk scores, informed by easily available clinical characteristics and common laboratory results, which may predict most intermediate-term mortality in populations with HF =72% to 75% accuracy.1,2 These risk scores, developed from patient cohorts in randomized clinical heart failure trials, may be accessed online or via handheld wireless devices. The Seattle Heart Failure Score is likely the most popular such tool used at present.

The present study by Barlera et al3 in this issue of Circulation: Heart Failure outlines a new predictive tool using data from 6975 participants in the GISSI-HF (Effects of n-3 PUFA and Rosuvastatin on Mortality-Morbidity of Patients With Symptomatic CHF) trial.4 In similar fashion to previous efforts, they identify 12 baseline clinical factors of which 6 were most predictive of death. These factors included increasing age (4% per year), followed by lower estimated glomerular filtration rate (<60 mL/min), ejection fraction <40% (2.5% per unit decrease), and systolic blood pressure. The presence of New York Heart Association class III or IV symptoms or chronic obstructive pulmonary disease also conferred a worse prognosis. Although performed in a small minority of patients (1231), increasing N-terminal pro-brain natriuretic peptide (NT-pro-BNP) and high-sensitivity troponin T (hsTnT) were very powerful predictors of mortality. The authors created a point system that could be used to estimate 2- and 4-year risk of mortality (up to 77%). In terms of statistical accuracy of the algorithm proposed by Barlera et al possessed slightly superior discriminatory value compared with the Seattle score, and the difference was small and could be partially explained by the lack of ability to account for 2 minor variables in the latter score- lymphocyte count and statin therapy (the latter was of course the randomized therapy of interest in GISSI-HF).

The primary advantages of this tool included the ease with which the score can be calculated (no website or complex calculations are needed) and transferred quickly to a mortality scale, coupled with the relatively large number of deaths (1969), and the inclusion of patients with either systolic or nonsystolic heart failure.

Why then, do most clinicians not routinely use such scores? The short answer is because they frequently do not help very much in making day-to-day practice decisions. Many reasons for this exist. First, risk scores, like most statistical analyses, perform well for large groups of individuals and for the intermediate term, but they perform very poorly for individuals, and for the short term. After all, for an individual, the percentage is either 100% an event will happen, or it is 0%. Real-world heart failure populations tend to be older and have much more severe comorbid conditions than populations in randomized clinical trials. Despite being a necessary component in trial design (it is done to enhance the relative likelihood of cardiovascular death during the trial to adequately test the efficacy of the cardiac intervention), it also lessens the external validity of the risk score. The time horizon of risk scores may span 1, 2, 4, or 5 years, which may not be an adequate time frame on which to make lifestyle decisions, particularly in younger, less severely afflicted patients. What do we tell young patients regarding 10-year survival for heart failure in this age of rapidly improving therapies for advanced heart failure, such as mechanical support?

Perhaps most importantly, risk scores for mortality rarely include nonfatal events and do not account for the quality of life changes associated with such nonfatal events. These assessments are invariably made by patients—even if they unaware of doing so. In an effort to measure the impact this phenomenon may have on choices for therapies in advanced heart failure, the time trade-off utility has been developed. In studies using this tool, patients are given an approximate life expectancy in their current situation and then are invited to estimate how much remaining life expectancy they would willingly trade to feel better. The results have shown that patients with decompensated heart failure will trade, on average, more than 30% or their predicted remaining life expectancy in order to feel significantly better. Further complicating the issue is that the time trade-off amount may change, particularly, as clinical status changes. Even in consideration of cardiac procedures ostensibly offered for prolongation of life, the discussions surrounding these procedures/therapies almost invariably gravitate to other potential outcomes such as side effects, complications, recovery time, and the degree to which these will cause suffering not only to them, but also to their families. We need more...
information on these types of outcomes and how they impact treatment decisions.

Many patients incur symptoms relating to noncardiac illnesses, such as arthritis or back pain, and wish noncardiac surgery for symptom relief. One patient I followed stated categorically that he would rather be dead than continue to have back pain. Does this mean his 12% perioperative mortality risk or 30% risk of prolonged ventilation/intensive care unit stay should disqualify him from the procedure? Not everyone of his family members agreed, much less those on his care teams. Current risk scores do not address these issues.

Finally, patients with heart failure are human, and so have families, friends, obligations, aspirations, fears, limitations, resources, and needs. Only some of these are directly related to their cardiac condition. Bad outcomes aside from death may affect patients with heart failure. These include the prospects of obtaining or maintaining a job or lifestyle, the ability to exercise or travel, or to participate in social activities or sexual activity. The possibility of financial ruin or excessive burden on family members may also be a critical factor, among others.

Such a complex interplay of factors cannot and should not be reduced to the binary outcome of alive or dead. This does not, however, mean risk scores should be avoided. Knowledge of prognosis, even if it is imprecise, is essential for optimal patient care. However, the intent should be that the risk informs rather than replaces the doctor-patient discussion. Indeed, there has been increasing attention to end-of-life care and how decisions are made. Several major societies, including the American Heart Association, the Canadian Cardiovascular Society, and the European Society of Cardiology, have all-published guidelines or position papers dealing with the patient with advanced heart failure and end-of-life care.7-9 Several common themes are emphasized as follows: (1) individual prediction of outcomes in individual patients with heart failure is inherently imprecise. This necessitates a discussion of patient values and preferences to inform clinicians of patient wishes; (2) these discussions are best accomplished relatively early in the course of the disease, rather than during a crisis event, with the discussion including those closest to the patient, such as family or significant other; (3) advanced directives may prove useful in many instances, not the least of which is the identification of a substitute decision-maker in event of incapacitation. This discussion should be revisited periodically and should be triggered by any important change in clinical status; (4) most importantly, modern palliative care should not be recognized as the only provision of comfort measures after withdrawal of heart failure therapy. Rather, it should be considered a vital part of patient care, including provision of advanced symptom control, and spiritual and emotional support of the patient and family. Indeed, we increasingly see inclusion of palliative care for patients who also receive active heart failure treatments.

Assessment of patient mortality risk is an essential part in any doctor-patient discussion, and Barlera et al have provided us with a new and useful tool that should be used to frame and inform the discussion. I have no doubt that in the future even better tools will be created. To further improve the conversation, we also need to better understand longer-term outcomes for younger patients and competing outcomes for older patients. We have to consider nonfatal adverse outcomes, both cardiac and noncardiac. Risk assessment tools need to be updated (preferably in real-world populations rather than those derived from clinical trials) as our therapies evolve over time. Evaluation and consideration of different cultural values should be developed.4 And above all, care providers must become facile in the art of shared decision-making with patients and their families. In this way, we allow the best possibility that patients will be empowered, involved, and treated in the manner and place of their choosing when they need it the most.

Disclosures
None.

References

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