

EDITORIAL COMMENT

Listening to Patients*

Edward P. Havranek, MD, FACC,†‡

Larry A. Allen, MD, MHS‡

Denver, Colorado

The paper by Stevenson et al. (1) in this issue of the *Journal* is, on first reading, an interesting report on how patients with advanced heart failure report their priorities for quality versus quantity of life using an arcane questionnaire called the time trade-off (TTO). On closer reading, however, the paper is much more than that. It is a call for cardiologists and patients to change the way they discuss choices about therapy.

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To understand how the results of this paper relate to everyday practice, some background about the concept measured by the TTO task—utility—is needed. A utility is a quantification of the strength of an individual person's preference for the possible outcomes of a decision. Although the primacy of preference in decision making has been promoted since at least the 19th century by philosophers such as John Stuart Mill, a quantitative way to measure preference when the outcomes of the decision are uncertain was first described by the mathematician John Von Neumann and the economist Oskar Morgenstern in 1944 as part of the foundation of game theory (2). This conceptualization of utility has subsequently been used widely in economics and public policy, but medical applications have been limited.

In a medical context, a utility measures the value an individual patient places on his or her current state of health. Based on theoretical considerations, utility is best measured with a set of questions called the standard gamble, in which a subject is asked to choose between accepting his or her current state of health and undergoing a procedure that can result in either death or perfect health. The risk of death associated with the procedure is varied until the subject is indifferent in a choice between current health state and taking a chance on the procedure. The TTO method, well described in the paper by Stevenson et al. (1), was

developed as an alternative to the standard gamble specifically for use in medical applications. Instead of being asked to choose between current health and a chance at perfect health, respondents are asked to choose between a length of time in current health and a shorter time in perfect health; the length of time in perfect health is varied until the subject becomes indifferent. It seems to be more easily interpreted by clinicians and patients, and gives results quantitatively similar to the standard gamble. Utility for health states can also be measured using multi-attribute questionnaires such as the European Quality of Life, 5-Dimension survey (3) and the Health Utilities Index (4), but their scoring is based on a correlation of standard gamble or TTO results from community subjects with questionnaire results.

Within the context of performing a prospective randomized trial (ESCAPE [Evaluation Study of Congestive Heart Failure and Pulmonary Artery Catheter Effectiveness]) evaluating tailored therapy based on hemodynamic measurements in patients with advanced heart, Stevenson et al. (1) had the foresight to incorporate survival preference questions into data collection. Utilities were measured by TTO at baseline, 3-month follow-up, and 6-month follow-up. As pointed out by the authors, baseline TTO values were similar to those obtained with this instrument in prior studies of patients with heart failure (5–7). They found a bimodal distribution of survival preferences. Approximately one-half of the patients expressed a preference for survival gains over improved health, and approximately one-fourth of the patients expressed a preference for much shorter survival but with better health; the remaining one-fourth of patients fell somewhere in the middle. In general, patients with more severe heart failure were willing to trade longer survival for better health, but illness severity predicted preferences poorly for individual patients. In measuring TTO over time, the current study goes a step further than prior studies, and provides us with a number of unique insights.

First, patients became more likely to value survival over better health during the transition from acute illness requiring hospitalization (baseline) to chronic illness managed in the outpatient setting (3-month follow-up). These preference changes mirrored the marked resolution in global well-being and symptom scales that occurred in the ESCAPE study regardless of treatment assignment (8).

Second, in the 6 months after the inpatient-outpatient transition, patient preferences remained remarkably stable. In aggregate, TTO measurements changed only 4% during long-term follow-up from 3 to 6 months. Thus, clinicians can be confident that measured preferences reflect, in part, characteristics intrinsic to patients and are a reliable basis for decision making.

The authors went on to assess the relationship between survival and preference for survival over better health. One-third of patients who survived <3 months had expressed willingness to trade away >90% of their remaining

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From the †Denver Health Medical Center and ‡University of Colorado, Denver, Colorado.

time for better health, compared with only 6% of those patients surviving through 6-month follow-up.

Although the study has limitations of an unfamiliar end point, missing data, and a narrow range of illness studied, none of these limitations changes the fact that the paper contains insights that are immediately useful to clinicians.

First, although patient beliefs, attitudes, and preferences generally align with those of physicians, they may be unexpectedly different in a substantial minority and must therefore be elicited explicitly. In the current study, patients willing to trade away a substantial proportion of survival did not differ significantly from other patients in regard to age, gender, ejection fraction, renal function, or blood pressure. These findings mirror those of a recent study in which heart failure patients, on average, overestimated their life expectancies by approximately 40% irrespective of disease severity or future survival (9). To elicit preferences, physicians must first have accurate knowledge not only of expected survival associated with therapy, but also of effects of therapy on quality of life. Unfortunately, many clinical trials of heart failure therapy have not provided us with data adequate to inform patients about expectations regarding quality of life.

Second, it is important that discussions with patients about their preferences take place when they are in a stable condition after acute exacerbations, as outlook seems to change importantly after hospitalization.

Thus, 2 patients meeting the same indications for an implantable cardioverter-defibrillator might make different decisions about implantation knowing that the device will prolong survival without improving their current state of health, and these patients may be indistinguishable by demographic or clinical characteristics. A patient who refuses an implantable cardioverter-defibrillator during hospitalization for an acute exacerbation might make a different informed decision if presented with the choice a few weeks later as an outpatient. Similar considerations apply to other common decisions with which clinicians and patients with heart failure are faced, such as decisions regarding coronary artery bypass surgery for patients with ischemic cardiomyopathy or mechanical circulatory support for patients failing

more conservative therapies. Recent calls have been made to begin incorporating patient preferences into national guidelines (10).

Simply put, we must ask patients with advanced heart failure how their current lives intersect with how they view death. Although some may be unable to answer, if we listen to those that do answer, we are likely to hear wisdom and courage we might otherwise have missed. Such insight is certain to help us better tailor care to the individual patients we treat.

Reprint requests and correspondence: Dr. Edward P. Havranek, Denver Health Medical Center #0960, 777 Bannock Street, Denver, Colorado 80204-4507. E-mail: ehavrane@dhha.org.

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