Patients Overestimate Survival Gain From ICDs

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CHICAGO — Most heart failure patients overestimate the survival benefit provided by implantable cardioverter defibrillators, according to a new survey, Dr. Garrick C. Stewart said at the annual scientific sessions of the American Heart Association.

The problem stems in part from the common practice of reporting clinical trial outcomes in terms of percent reduction in mortality. It creates confusion among patients, the public, and even physicians. This figure, which is also prominent in ICD marketing, is actually a percent of a percent and is far greater than the number of deaths prevented or delayed, which is what really matters, added Dr. Stewart of Brigham and Women’s Hospital, Boston.

“We advocate reporting event rates in persons per 100 to translate more clearly such information for our patients. We cannot stop reminding our patients and ourselves that heart failure remains a fatal disease from which most deaths occur slowly,” he stressed.

Dr. Stewart presented the results of a written survey completed by 104 patients with symptomatic heart failure who fit the profile of the study population in the landmark Sudden Cardiac Death in Heart Failure Trial (SCD-HeFT), which established the efficacy of ICDs for primary prevention of cardiac arrest. These were patients with an ejection fraction below 35% and no history of cardiac arrest or syncope. Two-thirds of the patients already had an ICD.

More than half of those surveyed said they expected an ICD would save at least 50 lives per 100 recipients over 5 years. Dr. Stewart noted, SCD-HeFT showed the benefit is 7-8 lives saved.

Frankly, the benefit is just not as big as we think,” said coinvestigator Dr. Lynne Warner Stevenson, codirector of the cardiomyopathy and heart failure clinic at Brigham and Women’s Hospital and professor of medicine at Harvard Medical School, Boston. “We frequently have patients referred to us from other centers where they’ve been told they must have an ICD put in place or they’ll die. We think that’s quite a disservice because it implies that the ICD will make them immortal.”

Two-thirds of survey participants who had an ICD thought the device would save their own lives. Fifty-five percent indicated they wouldn’t deactivate it even if they were getting daily shocks, 70% would keep it on if they were dying of cancer, and 100% would keep the device on even if they were continuously struggling to breathe.

Dr. Stewart and Dr. Stevenson both advocate a highly systematic approach to consenting patients for an ICD if they’ve never had a life-threatening arrhythmia.

“We actually have a script we use that says if we put an ICD in 100 patients with heart disease like yours, over the next 5 years we would expect that 30 patients would die anyway, 7 or 8 would be saved by the ICD, 10-20 would have a shock they don’t need, 5-15 would have other complications, and the rest would not experience their device at all,” Dr. Stevenson said.

After hearing all of this, roughly one-third of patients still want a device, one-third decide they definitely don’t, and one-third want to think it over some more.

Session chair Dr. Robert O. Bonow, chief of cardiology at Northwestern University, Chicago, said the fact that many patients believe an ICD will prevent them from dying may make them more lax in adhering to aggressive therapies aimed at slowing heart failure progression.

Underscoring the point that ICDs partially protect against sudden arrhythmic death but don’t prevent a slower death from pump failure, Dr. Jean-Yves F. Le Heuzey presented outcome data on 2,418 patients who got an ICD at 22 French hospitals during 2001-2003. Mortality was 11.3% by 2005. Every two percent of deaths resulted from pump failure, 8.7% from cardiac arrest with electromechanical dissociation, and 6.2% were due to arrhythmic storm. Cancer and septic shock each accounted for 6.5% of deaths, said Dr. Le Heuzey, professor of cardiology at George Pompidou European Hospital, Paris.

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DR. STEWART