

From Pacing and Clinical Electrophysiology

Patient and Cardiologist Perceptions on Decision Making for Implantable Cardioverter-defibrillators

A Qualitative Study

Dan D. Matlock, M.D., M.P.H.; Carolyn T. Nowels, M.S.P.H.; Frederick A. Masoudi, M.D., M.S.P.H.; William H. Sauer, M.D.; David B. Bekelman, M.D., M.P.H.; Deborah S. Main, Ph.D.; Jean S. Kutner, M.D., M.S.P.H.

Authors and Disclosures

Posted: 01/09/2012; Pacing Clin Electrophysiol. 2011;34(12):1634-1644. © 2011 Blackwell Publishing

Introduction

Many of the estimated 5 million patients in the United States with systolic heart failure are at high risk for sudden cardiac death (SCD) due to malignant ventricular arrhythmias.^[1] Implantable cardioverter-defibrillators (ICDs) offer an effective option to reduce the risk of dying from these lethal arrhythmias. Once used only for patients who had survived cardiac arrest (secondary prevention), ICDs are now used to reduce mortality for a substantial population of patients with advanced heart failure *at risk* for SCD (primary prevention).^[2,3] These primary prevention trials have led to changes in guidelines, which now include the recommendation of ICD therapy for all heart failure patients meeting criteria established by these trials (i.e., New York Heart Association class II or III heart failure symptoms, ejection fraction less than 35%).^[4] In fact, some researchers have proposed that the rate of ICD implantation in eligible heart failure patients should be a publicly reported quality measure.^[5]

Despite clear mortality benefits, the decision for patients to undergo ICD implantation for the purpose of preventing SCD is complicated. ICD therapy comes with potential risks, including increased hospitalizations,^[6] a lower quality of life if shocked;^[7,8] and an increased incidence of anxiety, depression, and posttraumatic stress disorder.^[9,10] Furthermore, ICDs can fail,^[9] deliver therapy inappropriately,^[11] and if not properly deactivated, cause significant suffering through unnecessary shocks at the end-of-life.^[12]

Patients have described receiving an ICD shock as similar to getting hit in the back by a "medicine ball."^[13]

Because ICDs involve trade-offs between clear benefits and risks, the patient's perspective is essential in deciding whether or not to undergo the procedure. The notion that patients should make informed medical decisions is well established in the legal and ethical realms,^[14] and the Institute of Medicine (IOM) has identified "patient-centered care" as one of the six aims of quality improvement, defining it as "providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions."^[15] Unfortunately, research suggests that patients are often not fully informed about recommended medical interventions such as ICD therapy.^[16,17] One study demonstrated that patients with ICDs overestimate their mortality benefits by 500%.^[18]

Accordingly, we conducted a qualitative study to assess cardiologist and patient perspectives on the factors important in making decisions about ICD implantation. For this analysis, we used patient-centered care as our theoretical framework. In addition to the IOM definition above, patient-centered care is based in the deeply rooted ethical and philosophical construct of autonomy, an essential aspect of personhood.^[19] Autonomy routinely trumps competing ethical principles such as beneficence and justice when challenged in legal settings.^[14] In this study, we aimed to understand current ICD decision-making practice, specifically exploring how the benefits and risks were discussed. In addition, we asked both patients and cardiologists if and how ICD decision making could be improved.