END OF LIFE MANAGEMENT OF ICDs: PATIENT PERSPECTIVES ON DEACTIVATION AND DONATION

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Background: Guidelines advocate discussion of end of life care of ICDs, including deactivation. Discussions might also address post-mortem donation of ICDs for product improvement or reuse overseas as pacemakers, to help reduce global health disparities.

Methods: We conducted a phone survey of ICD patients concerning advance directives (AD) and ICD handling at the end of life. Of 475 patients in a single device clinic, 61 lacked a working number, 198 were called but could not be reached, 7 were deceased or seriously ill, 6 had language or cognitive impairments, and 6 did not qualify due to changes in their medical condition. Of the 197 remaining, 44 declined to participate.

Results: 153 ICD patients (mean age 62, range 19-90, mean time since implant 5.43 years) completed the survey (77% response rate). Half (n=75, 49%) said they would like their ICD deactivated in an end of life illness. Most (n=128, 84%), thought that a do not resuscitate (DNR) order justified ICD deactivation. Over half (n=79, 52%) reported some form of AD. Although 26 (17%) reported ever thinking about ICDs in an end of life illness, only 2 had addressed it in an AD. Only 8 (5%) had ever discussed ICD deactivation with doctors. Nearly all (n=146, 95%) agreed patients should be given the option to fill out a living will specifically addressing end of life ICD care. When asked when, 41 (27%) said at implant, 71 (46%) at a follow up visit, and 22 (14%) at end of life. As for who should conduct the discussion, 73 (48%) said the electrophysiologist, 38 (25%) the cardiologist and 11 (7.2%) the primary care physician. Regarding donation of ICDs for product improvement and/or reuse, 134/151 (88%) would donate for product improvement, 131/151 (87%) would donate for reuse overseas, and 120/151(80%) for reuse in animals. When asked to chose one option, a plurality (n = 106/146, 72%) would donate for human reuse overseas.

Conclusions: ICD patients agree that discussions about ICDs and end of life are important. The majority supports the concept of an ICD-specific AD and post-mortem donation for product improvement/reuse, but has not considered or discussed these topics. Educational initiatives are warranted to help cardiovascular clinicians address end of life issues.