Chapter 10
Ethical Conundra in CIED Therapy: Ethical Implantation, Ethical End-of-Life Care

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Implantable cardioverter-defibrillators save lives in multiple populations of patients at risk for life-threatening ventricular arrhythmias, as described in prior chapters. However, ICD shocks are painful, described by patients as "being kicked by a mule" or "putting a finger in a light socket" [1], decreasing quality of life [2]. For a patient who otherwise has many years of quality life left, survival from cardiac arrest may be worth the trade-off of painful shocks. However, for those with life-limiting illnesses, shocks may create pain without meaningfully increasing lifespan. For patients with a previously implanted ICD now nearing the end of life, ethical patient care demands ongoing discussions of goals of care and how the options of continuing shocking function versus deactivation of the ICD may fit with current goals. Dying peacefully is valued by all – as described by relatives, peaceful death is an indicator of quality in palliative care [3].

For patients with apparent indications for ICD based on purely cardiac risk factors for sudden death [4, 5], ethical patient care demands holistic understanding of benefit of the ICD, as well as of patient goals and preferences. Implantation of an ICD in a patient with minimal chance of significant prolongation of life not only exposes the patient to risks of the procedure but to painful shocks.

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Ethical Implantation

Benefit and Comorbidities

Indications for defibrillator implantation for primary prevention, based on landmark trials showing benefit in patients with decreased ejection fraction and congestive heart failure and/or myocardial infarction, are well-known, and recent guidelines have changed little since 2008 [4, 5]. However, perhaps less widely known is the first class III indication in the guidelines, "ICD therapy is not indicated for patients who do not have a reasonable expectation of survival with an acceptable functional status for at least 1 year, even if they meet ICD implantation criteria specified in the class I, IIa, and IIb recommendations above *(Level of Evidence: C)*."[4] Palliative care experts are consulted not uncommonly regarding device activation in patients with recent implants [6], which has raised the question whether implanting electrophysiologists may ignore medical severe comorbidities that might limit the benefit of ICDs [6]. However, in one reported series [7] of patients requesting deactivation, the three patients in whom malignancy had been diagnosed prior to device implant had all been given greater-than-one-year life expectancies by their oncologist. The AMA Code of Ethics requires that physicians not impose on patients therapies which may be medically futile [8]. However, medical futility may be difficult to determine. A "reasonable expectation of survival for more than one year," a relatively "hard" endpoint, can already be difficult to predict in many cases; "reasonable expectation of survival with good functional status" even more difficult to define.

Two patient populations may require particular attention to comorbidities and expected functional status. To what extent ICDs benefit the elderly is an oft-raised question [9]. One editorialist has asked, "Is anyone too old for an implantable cardioverter-defibrillator" [10]? The median age in the landmark trials of ICD benefit has been in the 60s. While randomized trial data in the elderly are lacking, and results of meta-analyses variable [11, 12], other data do suggest benefit in the elderly. For example, while survival after ICD implantation is shorter in the elderly (as in any population), rates of appropriate device therapies are similar [13]. Two observational studies have suggested benefit in elderly—in a propensity-matched analysis of ICD patients in the Medicare population, the adjusted hazard ratio for mortality with an ICD was 0.62 [14], and in an analysis of the Get With The Guidelines population, HR was 0.71 [15]. In a subanalysis of the MADIT II trial, the subset of patients over age 75 years had greater benefit than younger patients [16]. In general, ICDs are less likely to decrease quality of life in the elderly than in the young [17].

However, it is clear that comorbidities play a critical role in survival benefit in this population. While age has minimal impact on surgical morbidity and mortality for device implantation, comorbidity significantly worsens procedural and in-hospital outcomes [18, 19]. In an analysis combining data from the National Cardiovascular Data Registry (NCDR) ICD Registry with Medicare data, 10% of ICD recipients met criteria for frailty, and those with this geriatric condition had a

1-year mortality twice that of those without; frailty in combination with other comorbidities such as COPD or diabetes synergistically increased mortality [20]. As comorbidities increase, ICD benefit decreases, particularly in the elderly [21].

Patients suffering from dementia represent another group in whom ethical care requires particular attention. As medicine continues to advance and life is increasingly prolonged, the number of patients going on to develop dementia is expected to increase from 35 million people worldwide currently to 115 million by 2050 [22]. One study combining data from the NCDR ICD Registry with Medicare data suggests that 1% of patients receiving a de novo ICD may suffer from dementia [20]. How ICDs impact quality of life in patients with dementia is unknown. Shocks increase catecholamines even in patients under deep sedation [23], and patients with dementia express pain through facial expression and changes in behavior [22].

Decision-making around de novo ICD implantation for those in the continuum from mild cognitive impairment to dementia requires careful discussion of risks and benefits in the context of patient values and preferences. Using data from the NDCR ICD Registry combined with Medicare, Green et al. found that 1% of those receiving de novo ICDs had dementia. Mortality in these patients was 27% at 1 year, similar to that in patients with solid tumors [20]. Mortality after a diagnosis of dementia in the general population is high, with an estimated median survival after onset of dementia of 1.3 [24] to 3.3 years [25], similar to that of more commonly recognized end-of-life conditions as metastatic breast cancer and stage IV congestive heart failure. Guidelines recommend against ICDs for patients in whom good functional status at 1 year is not expected [4], and many patients with advanced dementia will fall in that group. For individuals less severely impacted by dementia, shared decision-making around ICD implantation is crucial [26]. Ensuring that patients and families understand the risk of mortality after ICD implant, as well as the possibility of painful shocks, is critical to help patients and families think about ICD implant in the setting of the patient values and preferences. Proxies are less likely to choose aggressive interventions when they are aware of the poor prognosis carried by dementia [27]. However it may be particularly complicated to weigh the benefit/burden ratio of ICD implantation in patients with mild cognitive impairment or the earlier stages of dementia, because in general these patients have relatively maintained quality of life in the early stages, and as such patients and families may opt for decreasing the risk of sudden cardiac death.

Decision-Making Around ICD Implantation

For all patients, ethical device implantation requires a shared decision-making model as this option is discussed. Medicine has entered an era of patient-centered care, in which the paternalistic concept that doctors know best and should thus make decisions for their patients has been replaced by a model that fosters patient-clinician collaboration. Shared decision-making (SDM), termed the “pinnacle of patient-centered care,” is the process by which clinicians and patients work together to

develop care plans based on clinical evidence that balance risks and expected outcomes with patient preferences and values [26]. Making recommendations for an ICD without taking into account patients goals of care is inconsistent with medical ethical principles of autonomy [28]. For a patient with heart failure, the decision in considering an ICD is not between life and death but rather between accepting an ICD and having a potentially longer life with advancing heart failure or declining an ICD and having a potentially shorter life but maintaining the opportunity to die quickly [9]. Current heart failure guidelines specifically state that this trade-off should be discussed [29], and CMS now mandates a SDM interaction prior to CID implantation for patients prior to implantation of a device for primary prevention [30].

Data suggest that decision-making around ICD implantation is currently suboptimal. Multiple studies [31, 32], as recently as last year [33], show significant misunderstanding about risks and benefits of ICDs. One survey of physicians described that physicians avoided discussion of risks of ICD in order to steer the patient away from a "bad decision" [34]. Further, detailed interview studies of patients considering ICDs reveal multiple cognitive biases in both those who accept and those who decline the device, further complicating decision-making [32, 35]. Many patients report not being told of the option of not getting an ICD or not being asked whether they wanted the device [36].

The current CMS coverage decision mandates not just SDM, but use of an "evidence-based decision tool on ICDs" prior to implantation [30]. One example is found at https://patientdecisionaid.org/wp-content/uploads/2017/01/ICD-Infographic-5.23.16.pdf. In a recent Cochrane review [37] of 105 studies comparing use of decision-aids with general information for a variety of diseases, those using these tools felt better-informed with more accurate understanding of benefits and harms, as well as making decisions more consistent with their values. The tools did not worsen health outcomes and did not impact satisfaction. Early data evaluating the recommended tool for decision-making for primary prevention ICD implantation [38] suggested that it increased knowledge and satisfaction and reduced decisional conflict and regret. Further research is needed to determine whether widespread, mandated use of a decision-aid for patients undergoing ICD implantation will improve the decision-making process.

Ethical End of Life Care

For patients with an ICD implanted previously, ethical care as patients near the end of life mandates discussion of deactivation of the shocking function. The experience of dying patients receiving ICD shocks was first reported in the palliative care literature ("Death and Dying, a Shocking Experience" [39], "And It Can Go On and On and On…") [40]. Through interviewing families of recently deceased ICD patients, Goldstein et al. found that 20% reported that their family member received shocks in the last weeks, days, or hours of their lives [41]. This number was likely an

underestimate; however, as in many cases, family may not have been aware of shocks received. More recently, Kinch Westerdahl et al. [42] definitively determined the frequency of shocks while dying, performing postmortem ICD interrogation in 130 consecutive patients. Close to one-third received a shock in their last 24 h, many of whom had storms of over ten shocks, experiencing unnecessary pain while dying.

To what extent the failure to deactivate therapies stems from patient choice versus failure of the physician to communicate this option is unknown. Studies of patient preferences regarding ICD deactivation at end of life have shown mixed results. Several written surveys of ICD patients regarding preferences for ICD deactivation in hypothetical situations have found that patients may not wish deactivation even in the setting of constant dyspnea or frequent shocks [43]. In the only series of patients actually facing the decision in whom the option of deactivation was discussed – six patients with terminal malignancies, all with a history of treated ventricular arrhythmias – none chose to turn off shocking therapies [7]. However, we found, in a recent interview study, again a survey of hypothetical situations, putting ICD deactivation in the context of health outcomes such as functional and cognitive disability known to influence decision-making, that most would at least hypothetically choose deactivation in some situations [44]. Thus it is more likely that the high number of patients who die with device therapies active does so not out of conscious choice but because they did not know deactivation was an option.

In order to decrease shocks and improve quality of life in dying patients, the Heart Rhythm Society convened a multidisciplinary group of doctors, nurses, patients, lawyers, and ethicists, whose recommendations were published in 2010 in the "HRS Expert Consensus Statement on the Management of Cardiovascular Implantable Electronic Devices (CIEDs) in patients nearing end of life or requesting withdrawal of therapy" [45]. This document described the ethical and legal underpinnings of deactivation of ICDs and highlighted the importance of proactive communication around ICD deactivation by clinicians.

Ethical and Legal Principles Underlying Deactivation

As discussed in detail in the HRS document, deactivation of ICDs at a patient's request is strongly supported by both ethical principles and legal precedents. The primary ethical principle supporting the withdrawal of life-sustaining therapies is respect for autonomy [46]. In a series of cases addressing withdrawal of life-sustaining therapies, the US courts have ruled that the right to make decisions about medical treatments is both a common law (derived from court decisions) right based on bodily integrity and self-determination and a constitutional right based on privacy and liberty [47, 48]. A patient has the right to refuse any treatment, even if the treatment prolongs life and death would follow a decision not to use it [49]. US Supreme Court decisions have made a clear distinction between withdrawing life-sustaining treatments and assisted suicide and euthanasia. In the case of *Vacco v. Quill* [50], Chief Justice Rehnquist wrote, "The distinction comports with

fundamental legal principles of causation and intent. First, when a patient refuses life-sustaining medical treatment, he dies from an underlying fatal disease or pathology; but if a patient ingests lethal medication prescribed by a physician, he is killed by that medication... [In *Cruzan*] our assumption of a right to refuse treatment was grounded not…on the proposition that patients have a…right to hasten death, but on well established, traditional rights to bodily integrity and freedom from unwanted touching." Further, courts have ruled that there is no legal difference between withdrawing an ongoing treatment and not starting in the first place. Granting requests to withdraw life-sustaining treatments from patients, who do not want them, is respecting a right to be left alone and to die naturally of the underlying disease, a legally protected right based on the right to privacy. This has been phrased "a right to decide how to live the rest of one's life."

The Supreme Court has not specifically addressed the question of PM or ICD deactivation. However, the prior rulings did not focus on the specific therapy under question, but rather on "life-sustaining therapies." The law applies to the person, and informed consent is a right of the patient—it is not specific to any one medical intervention [49, 51–53].Thus, because cardiac implanted electronic devices deliver life-sustaining therapies, discontinuation of these therapies is clearly addressed by the Supreme Court precedents upholding the right to discontinue life-sustaining treatment—"Procedures don't have rights, patients do." Finally, these rights extend to patients who lack decision-making capacity, through previously expressed statements (e.g., advance directive) and surrogate decision-makers [51, 54, 55].

Importance of Early, Proactive Communication

Timely and effective communication is critical to prevent painful shocks in patients nearing the end of their lives. When first reported in 2004, few patients had discussed deactivation with their physicians prior to death [41].Ten and 15 years later, many patients remain unaware of the possibility of deactivation [31]. As evidenced by a survey in 2018, a third of patients remain insufficiently aware of ICD deactivation [33]. Similarly, mention of an ICD in an advance directive (AD) was rare in 2006 and 2007 [56, 57], and while the use of ADs is increasing, the proportion of ICD patients completing these remains under 50% [58]. Discussions of patients' goals for their medical care as illness advances have been shown to improve quality of life for these patients [59]. Patients and their families want these interactions with their physicians [60, 61], yet they happen too rarely [41, 45].

Not only is it ethically permissible to discuss with patients their wishes for their care at the end of life, but it is also an ethical imperative to do so. The first principle of medical ethics is autonomy [46], which includes the rights of a patient to self-determination and the duty of clinicians to respect the patient's wishes. Autonomy is maximized when patients understand the nature of their disease and all the options for treatment. These discussions should occur throughout the course of a patient's illness, and the early implementation of an advance directive will maximize a patient's self-determination should he or she become no longer capable of

decision-making, as well as decreasing ethical dilemmas and burden on caregiver surrogate decision-makers [45].

However, proactive communication by physicians regarding the option of ICD deactivation remains inadequate. Many barriers to these discussions have been identified [62, 63]. Clinicians report feelings that patients may not be "ready" or that such a discussion will destroy hope or general discomfort.

Clinicians must take a proactive role in discussions about the option of deactivation in the context of the patient's goals for care. These conversations should include a discussion of quality of life, functional status, perceptions of dignity, and both current and potential future symptoms, as each of these elements can influence how patients set goals for their health care [45]. These conversations should continue over the course of the patient's illness. As illness progresses, patient preferences for outcomes and the level of burden acceptable to a patient may change [64, 65]. Advanced care planning conversations improve outcomes for both patients and their families [59], as patients with ICDs who engage in advance care planning are less likely to experience shocks while dying because ICD deactivation has occurred [66]. Studies show that patients and families desire conversations about end-of-life care [60, 61, 67].

Palliative care consultation can also play a role [45, 68]. The goal of palliative care is to relieve suffering and improve quality of life for patients with advanced disease, and palliative care can be simultaneous with life-prolonging care [69]. Palliative care clinicians are expert at discussing values and preferences. Palliative care consultation has been associated with increased use of ADs in patients with ICDs [58]. However, cardiologists cannot abdicate responsibility for discussion with patients. As described by Quill, an overreliance on palliative care specialists may undermine the therapeutic relationship and further fragment care, and he has advocated a "sustainable model for palliative care" as involving both general physicians and palliative specialists [70].

Ongoing efforts may improve communication around ICD deactivation. An ongoing multicenter randomized trial, "Working to Improve Discussions About Defibrillator Management" (WISDOM), is currently evaluating the efficacy of a communication intervention to increase conversations about advance care planning between heart failure clinicians and advanced heart failure patients with ICDs [71], with the primary endpoint of a goals-of-care conversation between patients and clinicians and secondary endpoints ICD deactivation and patient and bereaved satisfaction with care. Incorporation of advanced care planning into the consent process at the time of implant has been suggested [72]. Training of cardiologists in communication around goals of care is critical [63, 73].

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