Lost in Translation
Examining Patient and Physician Perceptions of Implantable Cardioverter-Defibrillator Deactivation Discussions

Michael Mitar, MD; Ana C. Alba, MD; Jane MacIver, RN-NP, PhD; Heather Ross, MD, MHSc

Since its introduction into mainstream clinical practice in the 1980s, the implantable cardioverter-defibrillator (ICD) has become the treatment of choice for potentially life-threatening ventricular arrhythmias. ICDs are recommended by the American College of Cardiology/American Heart Association/Heart Rhythm Society in select patients as primary prevention to lower the risk of sudden cardiac death. Estimates of ICD prevalence in Canada number >110,000 people with an annual growth rate of 4%, which corresponds to an equivalent prevalence of >700,000 in the United States. ICDs work by sensing ventricular tachycardia and ventricular fibrillation and restoring the underlying rhythm via antitachy pacing (ventricular tachycardia) or through delivering an electric shock across the myocardium (ventricular tachycardia/ventricular fibrillation). Despite their proficiency in preventing sudden cardiac death, ICDs cannot remedy the underlying cardiac abnormality, hence patients ultimately develop progressive heart failure, a trajectory the ICD cannot improve. As their condition worsens, patients with heart failure may develop hypoxia, sepsis, and electrolyte imbalances, which can serve to further potentiate arrhythmia, subsequently increasing shock frequency. ICD shocks may in this setting become undesirable.

ICDs have been unequivocally shown to prolong life. However, in some patients they do so at the expense of painful shocks that diminish patients’ self-perceived quality of life. Approximately 30% of ICD patients experience shocks in the minutes before death. Some patients have likened these electric shocks to being kicked in the chest by a horse. In an investigation comparing quality of life measures in ICD patients and those administered a pharmacological intervention, both physical and psychological functioning were diminished in the ICD group, especially in those who received >5 shocks. Furthermore, the generally adverse and unpredictable timing of an ICD shock was found to be a source of psychological distress. The number of years since implantation and number of ICD discharges were also positively correlated with anxiety, which occurs in 13% to 38% of patients. This psychological burden is occasionally transferred to the patient’s family because both patients who received shocks and their family members possessed higher levels of mood disturbance than shock-naive patients. In addition, these symptoms may predispose to arrhythmia, potentially increasing one’s propensity for future shocks.

Deactivation of an ICD involves reprogramming the device or using an external magnet to disable the ICD’s shocking and antitachycardia pacing functions. It is warranted under circumstances in which the continued use of ICD is inconsistent with patient goals, and death is largely inevitable. Patients may decide that a quick unpredictable death from arrhythmia is preferable to a slower less comfortable demise from heart failure. Recommendations from the American College of Cardiology/American Heart Association/Heart Rhythm Society include providing patients with information regarding ICD deactivation. The recent Heart Rhythm Society expert consensus highlights the legal, ethical, and religious issues surrounding device deactivation, the importance of communication, and provides a management approach for clinicians regarding ICD deactivation. Despite this recommendation, these conversations rarely occur. The purpose of this article is to identify and review studies evaluating factors affecting ICD deactivation discussions in patients with heart failure.

Methods of Literature Search
A systematic search of the MEDLINE, PsycINFO, EMBASE, and Cochrane Library databases was undertaken using the MESH terms “Defibrillators, Implantable,” “withholding treatment,” “terminal care,” “attitude to death,” “decision making,” “palliative care,” and “euthanasia, passive” on January 2012. To ensure thoroughness of the search, the text words “quality of life,” “device deactivation,” and “withdrawing treatment” were also used. Additional studies were identified through included articles’ reference lists. No limitations were placed on year of publication, but only articles in English were included. There were no restrictions placed on subpopulations of ICD patients, physician specialties taking responsibility for deactivation discussions, or study design. The search yielded 16 primary research articles that specifically addressed ICD deactivation discussions. Six studies evaluated patient and next-of-kin attitudes, whereas 10 studies analyzed physicians’ attitudes toward ICD deactivation discussions.
Patient and Next-of-Kin Attitudes Toward ICD Deactivation Discussions

Table 1 summarizes patients’ attitudes toward ICD deactivation discussions. The results of these studies suggest that patients’ reluctance to engage in ICD deactivation discussions may evolve from their misunderstanding of the role and function of ICD.

Patients’ Understanding of the Role and Function of ICD

Patients’ attitudes regarding ICD deactivation might evolve from their misperceptions regarding the role and function of ICD. Using qualitative methods, Goldstein et al. interviewed 15 ICD patients regarding their understanding of the device and attitudes toward device deactivation. The findings were consistent among patients with and without previous ICD shocks. More than half the sample (53%) had experienced at least 1 ICD shock. The majority of patients misunderstood the purpose of ICD. Some described it like a pacemaker, used exclusively as a regulator of heart rhythm and rate. They did not appreciate it as a safeguard against sudden cardiac death, seeing their ICD as exclusively benevolent, unable to appreciate any circumstance under which the device could cause harm. In fact, most patients refused to discuss deactivation, likening it to committing suicide. None of the participants recalled having discussed device deactivation with their physicians, and when asked, most expressed a desire to defer deactivation decisions to their physicians. Importantly, none of these patients was considered to be nearing end-of-life. Terminally ill patients may also be unwilling to consider ICD deactivation. Kobza and Erne²⁰ examined a cohort of 272 ICD patients, of which 8 had some form of malignant tumor. Although device deactivation education was provided, the majority of patients (75%) refused to consider deactivation, associating ICD deactivation with imminent death. These findings were independent of the indication, because those with both primary and secondary prevention ICDs held identical beliefs. This misinformation may discourage patients from considering ICD deactivation as a viable option and may be why patients defer treatment decisions to their physicians.

Stewart et al.²¹ surveyed 105 patients with heart failure, who were predominantly men (70%), predominantly ischemic heart failure, and an average age of 58 years, about their expectations regarding ICD prevention of sudden cardiac death. Of patients with an ICD (n=67; 64%), 73% were aware that the shock function could be deactivated. When asked about their preference for ICD deactivation should they become terminally ill, most indicated they would not deactivate the device. Over half said they would keep their device active even if they were experiencing daily shocks, dying of cancer, or knew they would be dead within 1 month. Patients consistently overestimated their life expectancy, with 65% expecting to live for at least 10 years. As with Goldstein et al.,²⁰ these results support that patients who do not anticipate imminent death perceive device deactivation as an act of suicide, especially if they perceive their device as beneficial and responsible for their continued existence.

Kirkpatrick et al.²² conducted a single-center survey of 278 patients to assess whether patients had ICD-specific advance directives. Although 50% of the patients had some form of advance directive, only 2% specifically addressed ICD deactivation. Furthermore, 96% of the sample had no established plan for their device in an end-of-life scenario. When asked when the ICD advance directive discussion should be initiated, most stated that follow-up visits or end-of-life was the most appropriate time (34% and 40%, respectively).

Patients view their devices as lifesaving, unable to fathom life without the protective net that is their device, independent of whether or not they have experienced a shock.¹⁹ The long lag time between device implantation and end-of-life presumably plays into this belief because patients view their ICDs as the source of their continued asymptomatic survival.¹⁹–²² In this

<table>
<thead>
<tr>
<th>Study</th>
<th>Study Design</th>
<th>Population</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Goldstein et al.²⁰</td>
<td>Qualitative, focus groups</td>
<td>n=15</td>
<td>Ambulatory ICD patients</td>
</tr>
<tr>
<td>Kobza and Erne²⁰</td>
<td>Retrospective chart review</td>
<td>n=8</td>
<td>ICD with malignancy</td>
</tr>
<tr>
<td>Stewart et al.²¹</td>
<td>Survey Multicenter</td>
<td>n=105</td>
<td>HF patients±ICD</td>
</tr>
<tr>
<td>Kirkpatrick et al.²²</td>
<td>Telephone survey</td>
<td>n=278</td>
<td>ICD patients</td>
</tr>
<tr>
<td>Lewis et al.⁹</td>
<td>Retrospective chart review</td>
<td>n=63</td>
<td>Deceased ICD patients</td>
</tr>
<tr>
<td>Goldstein et al.⁸</td>
<td>Retrospective cohort, telephone survey</td>
<td>n=100</td>
<td>Next of kin of deceased ICD patients</td>
</tr>
</tbody>
</table>

ICD indicates implantable cardioverter-defibrillator.
regard, deactivation is erroneously equated with physician-assisted suicide. This misconception is further complicated by the patients’ indication for ICD implant. Patients who have an ICD because they have experienced a life-threatening arrhythmia (secondary prevention) may equate the device with life support, where withdrawal would mean death. Patients who have an ICD implanted as primary prevention may have little disease burden and no experience with cardiac arrhythmias. They may attribute their asymptomatic status to the ICD and, therefore, refuse to discuss deactivation. Furthermore, the discrete internal nature of the device contributes to this notion by essentially becoming a necessary component of the patient’s being.

Patients seem to be more receptive to ICD deactivation discussions when they know they are nearing end-of-life. Lewis et al.8 completed a retrospective chart review of 63 patients, 20 with a terminal disease diagnosis and 43 without, to evaluate the strategy of discussing ICD deactivation with patients who developed a terminal illness. Identification of a terminal illness triggered a discussion regarding prognosis, end-of-life treatment preferences and the potential for device deactivation with the patient and family, and their physician care team. With this strategy, 100% of patients (20) with a terminal illness elected to have their defibrillator deactivated before death, regardless of their ICD implantation indication. The time between device deactivation and death was ≈49 days, and few patients experienced a shock within 1 month of death. Conversely, those with nonterminal illnesses were less likely to engage in device deactivation discussions, resulting in administration of shocks closer to the time of death (260 days versus 536 days). These results are similar to the study by Goldstein et al,19 which demonstrated that patients with a terminal disease counseled on device deactivation were more likely to be offered, and choose, ICD deactivation.

**Next-of-Kin Experiences With ICD Deactivation Discussions**

Goldstein et al.8 performed a cross-sectional study of the next of kin of 100 patients who had an ICD and died. They sent surveys asking about the next of kin’s end-of-life care and whether ICD deactivation discussions occurred before the loved one’s death. Information regarding cause of death, frequency, and timing of shock therapy was collected. Seventy-eight percent of the patients had Do Not Resuscitate orders and 63% had advance directives. Twenty-seven patients (27%) experienced an ICD shock within the last month of life, and 9% were shocked immediately before dying. Only 27 (27%) patients had discussions regarding ICD deactivation, with most occurring within the last days of life. Of the 27 patients in whom ICD deactivation was discussed, the vast majority (78%) chose to deactivate the device. Goldstein et al. postulate that the physicians’ decision to discuss ICD deactivation was largely reactive based on an overdue response to suffer immediately before death.

**Physicians’ Attitudes Toward ICD Deactivation Discussions**

Table 2 summarizes studies of physicians’ attitudes toward ICD deactivation discussions and potential barriers to discussion, predominantly data from survey studies. It is important to note that although the sample sizes of the studies may be adequate, the response rate is generally low. We do not know whether the knowledge and attitudes of the clinicians who did not respond are similar to those who responded. Regardless, these studies identify that many physicians are misinformed about the role and function of ICD and the legal and ethical implications of device withdrawal. In addition, although most physicians acknowledge the importance of discussing ICD deactivation with patients who are dying, many are reluctant to engage in these discussions.

**Physicians’ Knowledge Regarding the Role and Function of ICD**

Kelley et al.23 randomly surveyed cardiologists, electrophysiologists, and geriatricians to ascertain physicians’ knowledge, attitudes, and practices regarding ICDs in patients at end-of-life and received 558 responses (12%). The survey consisted of 5 patient vignettes exploring different end-of-life scenarios where ICD deactivation might be considered. The severity of the vignette’s clinical picture was positively correlated with physician willingness to discuss deactivation. Electrophysiologists were the most willing to initiate discussions, but only 20% actually engaged in these discussions. Geriatricians and general internists were willing to initiate these discussions but identified they had insufficient information about device deactivation and did not recognize the painful nature of shock therapy. Over half (58%) of respondents identified a need for expert guidance.

**Misperceptions Regarding the Ethical and Legal Implications of ICD Deactivation**

Sherazi et al.26 conducted a cross-sectional study (n=87) assessing physicians’ knowledge of medical, legal, and ethical issues involved in ICD deactivation. Forty-six percent of participants stated that ICD deactivation was illegal and 18% questioned its ethicality. Physicians who thought that the practice was illegal or unethical were more likely to be general internists or geriatricians. All cardiologists and electrophysiologists questioned considered ICD deactivation legal and ethical. Kapa et al.27 similarly conducted a survey to determine the legal and ethical beliefs of physicians, lawyers, and patients regarding ICD deactivation at end-of-life. Presented with a scenario where a terminally ill patient requested ICD deactivation, the majority of participants felt that ICD could be deactivated. However, 37% of lawyers felt that deactivating the ICD was not in the best interest of the patient, and a further 10% considered ICD deactivation an act of physician-assisted suicide or euthanasia. Most physicians did not share these beliefs. Kramer et al.28 found that physicians were less comfortable discussing ICD deactivation than discontinuing other lifesaving treatments, such as dialysis and mechanical ventilation. Of the respondents, 48% thought that ICD deactivation was morally distinct from other forms of withdrawal, and 20% felt that ICD deactivation could render them legally liable; however, only 2% of respondents sought some form of legal consultation before initiating management.
Perceived Barriers to ICD Deactivation Discussions
The American Heart Association recommends that information about ICD deactivation be discussed before device implantation and after any major change in patient status to ensure that ongoing ICD use is consistent with the patient’s goals of care. However, few physicians engage in these discussions even when a patient is nearing end-of-life. Using a qualitative approach, Goldstein et al interviewed 12 physicians (2 general internists, 2 geriatricians, 4 cardiologists, and 4 electrophysiologists) who cared for patients with ICDs.
to describe physicians’ perceptions about end-of-life ICD care. All participants responded that they rarely engaged in deactivation discussions. They equated device deactivation with the withdrawal of life-sustaining care, wherein death is directly caused by the withdrawal of care. Some were concerned that initiating ICD deactivation discussions would quell any remaining hope that a patient may have. Finally, physicians were reluctant to engage in discussions regarding device deactivation when they felt there was insufficient time for rapport with patient or family. Despite the presence of these self-reported barriers, all clinicians expressed an interest in playing a role in these discussions. Note that the physicians who participated in this study were relatively young (median age, 36 years) and had been practicing for <5 years. Their limited experience may explain why so few discussions had occurred. As this physician group gains experience with initiating these discussions, their frequency can be expected to rise. Marinskis and van Erven66 corroborated these results in a survey of European physicians reporting that 62% of physicians would consider ICD deactivation, but only 4% routinely did.

Morrison et al31 surveyed 150 hospice and palliative care physicians to elucidate their experiences and biases regarding ICD deactivation. Although most physicians strongly agreed that it is appropriate to disable an ICD (93%), they had little actual experience in initiating these discussions. Given their lack of familiarity and training with ICD deactivation, 83% of physicians felt that they would benefit from some form of formal conversational protocol outlining end-of-life ICD management. In fact, a history of prior experience with ICD deactivation is the strongest predictor of physician willingness to initiate ICD deactivation discussions.31,32

In their survey of physicians’ knowledge, attitudes, and practice regarding ICD deactivation discussions, Kelley et al32 reported that 35% of respondents (n=558) stated that the initiation of ICD deactivation discussions would be contingent upon factors, such as resuscitation status and clinical picture. About 21% said that alternative therapy should be considered before shutting off the device, whereas 12% advocated postponing the discussion indefinitely. Seventeen percent of physicians stipulated that patients were responsible for broaching the subject. A small number of physicians refused to deactivate a device citing euthanasia and physician-assisted suicide as justifications. When Mueller et al33 surveyed 787 physicians and device industry representatives, almost half of the physicians (43.3%) who had deactivated an ICD admitted to being uncomfortable with the intervention.

In heart failure, patient prognosis is often difficult to predict because of the remitting/relapsing nature of the disease. Hauptman et al34 reported that only 15.7% of 734 physicians surveyed felt they could reliably predict the timing of death, whereas the majority admitted to being able to formulate such an assessment rarely (25.2%) or only sometimes (59.1%). Confidence in predictive capabilities was higher in geriatricians than cardiologists or family physicians and was more common in those with palliative care training. This confidence did not correlate with the frequency of deactivation discussion, because those who were least confident in predicting survival were most likely to consider ICD deactivation discussions (cardiologists 87%, geriatricians 78%, internal medicine/family physicians 70%) and had engaged in at least one such conversation with patients and their families (cardiologists 75%, geriatricians 40%, internal medicine/family physicians 25%). There was a significant discrepancy between physicians’ perceived abilities and their roles in the treatment of end-stage heart failure.

ICD Deactivation Discussions: A Practical Approach

The studies conducted to date suffer from several methodological deficiencies, including small sample size, questionnaire reporting bias, reliance on patient/next-of-kin report, and observational design. Further research is needed to develop strategies for initiating ICD deactivation discussions and to address the timing of these discussions. However, the results of these studies identify clinically relevant gaps in the care of patients with ICDs. As the population ages and the prevalence of heart failure increases, the use of ICD devices will continue to rise, ultimately increasing the need for ICD deactivation discussions. The following recommendations will lead to the integration of ICD deactivation discussions into existing advance care planning and can help physicians provide care that is congruent with the patients’ goals for end-of-life care.

ICD Deactivation Is Legal and Morally Acceptable

Physicians have a tendency to overestimate the potential benefits and underestimate the potential harm of ICDs. In keeping with the principle of beneficence, physicians are obliged to dispel misinformation and allow patients to die with dignity and of their own accord.36 Where ICD deactivation is consistent with patient goals, physicians must initiate deactivation discussions and describe such an intervention as both a viable and ethical option.34,36 It is critical that physicians remember that deactivating the device does not cause death but allows the natural disease trajectory to occur and in no way represents a form of assisted suicide or euthanasia. Furthermore, physicians should engage in discussions regarding end-of-life care before and after device deactivation, thereby acknowledging that death does not occur as a result of ICD withdrawal but rather as a natural consequence of the patient’s disease process.

Develop and Implement a Conversational Protocol for ICD Deactivation Discussions

Emphasis must be placed on physicians’ education regarding ICD deactivation.26,33 Because lack of experience is often cited as a mitigating factor, educational interventions should be aimed at all levels, including medical students and residents, to increase exposure and comfort level.24 It is important to ensure that the care team, regardless of its structure, is able to adequately address ICD deactivation. Furthermore, participating in a formal palliative care rotation may help build skills in both prognostication and communicating this information to patients and their families.34,37 It would also be prudent to institute a conversational protocol, whereby physicians are provided with a guideline for ICD deactivation. These formats have been shown to increase the rate of ICD deactivation among patients when delivered at the time of hospice
admission. Future research is needed to determine the best educational strategy and target audience for these protocols.

**Accept Responsibility for ICD Deactivation Discussions**

Expecting patients to raise the issue of ICD deactivation is unrealistic. General internists and geriatricians are willing to initiate discussions, but their limited knowledge regarding the role and function of ICDs may limit their ability to facilitate such discussions. Electrophysiologists have the greatest knowledge of ICD function but are least likely to initiate ICD deactivation discussions. Their interactions with patients are generally limited to episodic encounters related to device function, and many are not responsible for ongoing patient care. Cardiologists, who are intimately familiar with ICD function and, by virtue of their patient population, frequently engage patients with heart failure in end-of-life discussions, are uniquely suited to assume responsibility for ICD deactivation discussions. What is notably absent in the literature is the knowledge, attitudes, and beliefs of heart failure cardiologists. The knowledge, attitudes, and practices of this group need to be explored in greater detail.

**Include ICD Deactivation Discussions During Advance Care Planning and End-of-Life Discussions**

Deactivation of an ICD is desirable to avoid unnecessary pain and distress for patients and their families when patients near end-of-life. Advance care directives could serve as the impetus for the initiation of device deactivation discussions. It is reasonable to discuss advance directives and ICD status simultaneously to ensure goal congruency. Although a valuable catalyst to ICD deactivation discussions, advance directives discussions should be only one of many discussion landmarks throughout the course of a patient’s disease, beginning before device implantation and continuing until death. Given the highly unpredictable nature of heart failure, the “early and often” strategy is ideal, whereby advance care directive discussions, including ICD deactivation, occur soon after diagnosis, with ICD implantation and again with any significant change in the course of their illness. Further research is needed to examine patient preferences for deactivation discussion timing and dynamics as the unpredictability of heart failure precludes the establishment of clearly defined clinical discussion landmarks.

**Conclusion**

There is a paucity of literature examining patient and clinician attitudes to end-of-life ICD deactivation discussions, severely limiting this population’s ability to receive treatment or treatment withdrawal consistent with their goals of care. Published studies cite a need for improved understanding of the nuances of ICD implantation and deactivation by physicians and patients, as well as greater information transfer among these groups. Furthermore, there exists a need for a well-formalized protocol outlining an approach to the initiation of ICD deactivation discussions. This protocol should also contain references to the ethical and legal issues, ensuring patients are aware of the appropriateness of ICD withdrawal and its consistency with their goals of care. These discussions are best addressed within a broader discussion of end-of-life directives and should be addressed both in general terms outlining overall goals and in specific terms emphasizing the ICD itself. As a patient’s values and attitudes are subject to change and often do so within a changing clinical picture, these issues should be revisited periodically to ensure consistency between patient preferences and stated goals of care.

**Disclosures**

None.

**References**

13. Dunbar SB. *Adaptation to the Internal Cardioverter Defibrillator* [final technical report for National Institute of Nursing Research grant R01NR0304]. Atlanta, GA: Emory University;1996.
17. American Heart Association: 2009 Focused Update: ACCF/AHA Guidelines for the Diagnosis and Management of Heart Failure in Adults; a report of the American College of Cardiology Foundation/American Heart


Key Words: defibrillation – heart failure – implantable cardioverter-defibrillator – end-of-life care
Lost in Translation: Examining Patient and Physician Perceptions of Implantable Cardioverter-Defibrillator Deactivation Discussions
Michael Mitar, Ana C. Alba, Jane MacIver and Heather Ross

Circ Heart Fail. 2012;5:660-666
doi: 10.1161/CIRCHEARTFAILURE.112.967497

The online version of this article, along with updated information and services, is located on the World Wide Web at:
http://circheartfailure.ahajournals.org/content/5/5/660

Permissions: Requests for permissions to reproduce figures, tables, or portions of articles originally published in Circulation: Heart Failure can be obtained via RightsLink, a service of the Copyright Clearance Center, not the Editorial Office. Once the online version of the published article for which permission is being requested is located, click Request Permissions in the middle column of the Web page under Services. Further information about this process is available in the Permissions and Rights Question and Answer document.

Reprints: Information about reprints can be found online at:
http://www.lww.com/reprints

Subscriptions: Information about subscribing to Circulation: Heart Failure is online at:
http://circheartfailure.ahajournals.org//subscriptions/