Deactivation of Implantable Cardioverter Defibrillator in Patients With Terminal Diagnoses

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Implantable cardioverter defibrillators (ICDs) prevent sudden cardiac death. However, in patients with terminal illnesses, these devices may disrupt the dying process. This study was undertaken to review our current strategies surrounding device deactivation. A retrospective chart review was performed at Kingston Health Sciences Centre of patients with an ICD who died from 2015 to 2018. Data collected included patient demographics, clinical details surrounding device implantation, patient co-morbidities leading to deactivation, time to deactivation, physical place of deactivation, and device programming information. Ethics approval was obtained from the Queen's University Health Sciences Research Ethics Board. A total of 49 patients were included for analysis. Mean age at the time of death was 77.5 years (range: 57 to 94 years) and 12.2% (6/49) were women. The indications for ICD implantation were primary prevention of sudden cardiac death in 69.4% (34/49) and secondary prevention in 30.6% (15/49). Deactivation as part of end-of-life care was performed in 32.7% of patients (16/49). Deactivations occurred in clinic in 6.1% (3/49) of patients, on hospital inpatient wards in 12.2% (6/49) of patients, and in critical care settings in 14.2% (7/49) of patients. The remaining 67.3% (33/49) of patients died with fully functioning devices in place. The most prevalent terminal diagnoses were metastatic cancer (22.4%) and end-stage congestive heart failure (20.4%). On average, patients had their devices deactivated 13 months (range: 0 to 62 months) after their terminal diagnosis was established. Once a patient was documented as Do Not Resuscitate (DNR), deactivation was discussed and carried out within a mean time of 38 days (range: 0 to 400 days). Seven patients had their device active for more than 1 month after being documented as DNR. Ten patients (20.4%) received ICD shocks after their terminal diagnosis, 9 received shocks in the month before death, and 2 received shocks after formal DNR orders were in place. Approximately one-third of patients with ICDs received deactivation of their cardioversion/defibrillation therapies as part of their end-of-life care plan. A relatively high proportion of patients (20%) received an ICD shock in the last month of life. In conclusion, addressing device programming needs, including deactivation of cardioversion/defibrillation therapies, should be considered in the context of a patient's goals of care in every patient with an ICD who has a co-existing life-limiting diagnosis. **© 2019 Elsevier Inc. All rights reserved.** **(Am J Cardiol 2019;124:1064−1068)**

Many patients with a terminal illness such as metastatic cancer have pre-existing cardiac disease. Cardiac disease and cancer are the most common causes of death in industrialized nations,[1] are prevalent in the aging population, and share predisposing risk factors such as tobacco use, sedentary life style, obesity and/or an unhealthy diet.[2] Implantable cardioverter defibrillators (ICDs) have become the standard of care for both primary and secondary prevention of sudden cardiac death in patients at risk for ventricular arrhythmia.[3] Shocks from these devices are known to be painful.[4,5] In the patient with a terminal illness, who has transitioned to a comfort-focused approach and no longer wishes to prevent sudden cardiac death, there is a risk that a shock could be delivered at the end of life. These shocks can cause pain and suffering in the dying patient, which adds additional distress to the patient, family and to the health care professionals involved.[6] This retrospective study aims to investigate how device deactivation in patients with terminal illness is occurring at our tertiary care hospital; Kingston Health Sciences Centre (KHSC) in Kingston, Ontario, Canada.

Methods

A retrospective single center study of all patients who died from 2015 to 2018 with an ICD in situ was undertaken at our institution. This study was approved by the Queen's University Research Ethics Board.

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The study population consisted of all patients who had an ICD that was either deactivated or explanted during the study time-frame. Patients were excluded if device deactivation or explantation took place for reasons other than death or a terminal illness. Patients were defined as having a terminal illness if they were diagnosed with a medical condition which had a statistical mean life expectancy of less than 2 years. This included patients with stage IV cancer, congestive heart failure with New York Heart Association class IV disease, cirrhosis with Child-Pugh Class C disease, and very severe chronic obstructive pulmonary disease with a forced expiratory volume at one second of less than 30% of predicted.[7–9] We also included patients who, when their entire clinical case was taken into account, were identified as high risk for death in the foreseeable 12-month period.[10] This included patients with multimorbidity (Charlson Co-Morbidity Index score of 5 or greater) or a Clinical Frailty Scale of 7 or higher.[11,12]

Data collected included patient demographic information on age at time of death, gender, date of device implantation, and date of device deactivation. Device-specific information was collected on indication for implantation, type of device (single-chamber, dual-chamber, or cardiac resynchronization therapy defibrillator), device manufacturer, model, and device remote programming ability. The following patient clinical information was collected: terminal diagnosis leading to device deactivation, date of first discussion around deactivation, Do Not Resuscitate (DNR) status, and the date DNR status was established. Device interrogation data were examined to identify if and when therapies had been delivered to the patient by the device, along with the rhythm diagnosis at the time of therapy delivery. These data were then entered into an encrypted Microsoft Excel spreadsheet for later analysis.

Results

A total of 49 deceased patients were identified who had an ICD in situ before death and who were followed in clinic from 2015 to 2018. Population, device, and implantation characteristics are shown in Table 1. Causes of death are given in Figure 1. The most common causes of death were metastatic cancer in 22.4% (11/49) and congestive heart failure in 20.4% (10/49). A remaining 28.6% of patients (14/49) had incomplete charts with no clearly identified cause of death; this usually occurred when patients presented to a regional primary or secondary care hospital just before dying and therefore had incomplete charts at KHSC.

Table 1
Patient characteristics (n = 49)

Age (yrs)	77.5
Men	43 (87.8%)
Type of device	
Single-chamber ICD	33 (67.4%)
Dual-chamber ICD	11 (22.4%)
CRT-D	5 (10.2%)
Indication for implantation	
Primary prevention	34 (69.4%)
Secondary prevention	15 (30.6%)

Patient demographic information, device type, and clinical indication for ICD implantation.

Only 40.8% (20/49) of patients who died with an ICD and a terminal diagnosis had a DNR order from a physician. Of these DNR patients, 80.0% (16/20) underwent device deactivation as part of their end-of-life care plan. The remaining 59.2% (29/49) of studied patients, died with physician's orders in place to be "Full Code" (i.e., wishing to have an attempt at cardiopulmonary resuscitation) with their ICD cardioversion/defibrillation therapies active (Figure 2).

Patients who opted to pursue device cardioversion/defibrillation therapy deactivation after opting to be DNR did so for a variety of reasons. Those patients with metastatic cancer (7/16 or 43.75%) all did so due to disease progression with death seen as imminently foreseeable in the coming weeks to months. All 7 (43.75%) had a significant functional decline that made them either fully bed-bound or nearly-bed bound with greatly limited mobility. All patients with congestive heart failure (4/16, 25%) who underwent device deactivation did so due to an acute presentation to the emergency department with multiorgan failure in the setting of refractory cardiogenic shock. Patients with dementia (2/16, 12.5%) underwent device deactivation due to disease progression which resulted in an unacceptable/poor quality of life which was identified in the out-patient setting, resulting in out-patient device deactivations. A further two patients (2/16, 12.5%) were identified who underwent device deactivation due to advanced clinical frailty; both of those deactivations took place in the in-patient setting after medical therapies did not improve the patient's functional status. One patient (6.3%) of the 16 patients who underwent device deactivation did so due to progression of an underlying congenital condition (Fabry's disease) which resulted in multi-organ failure despite medical interventions during a protracted in-patient course in hospital. Device deactivation rates were not statistically different between devices implanted for primary prevention vs. secondary prevention.

On average, 383 days (~13 months) elapsed between the establishment of a patient's terminal diagnosis and the formal deactivation of their device's cardioversion/defibrillation therapies. Only 30.6% of patients (15/49) had a completed KHSC "Patient's Goals of Care Discussion Form" on their chart despite these forms being a part of the formal admission paperwork package for all patients at KHSC. Of note, only 1 (2.0%) patient's Goals of Care Discussion Tool mentioned that the patient had an active ICD in situ. Those patients with DNR in place had a mean time from DNR to device deactivation of 38 days (range: 0 to 400 days). A significant percentage of patients (14.3%) had their device active for more than 1 month after having a DNR order documented.

ICD therapy deactivation, as part of end-of-life care, occurred in clinic in 6.1% (3/49) of patients, on hospital inpatient wards in 12.2% (6/49) of patients, and in critical care settings in 14.2% (7/49) of patients. The remaining 67.3% (33/49) of patients died with fully functioning devices. If a patient died with a functioning device, the device was deactivated postmortem at either the morgue or funeral

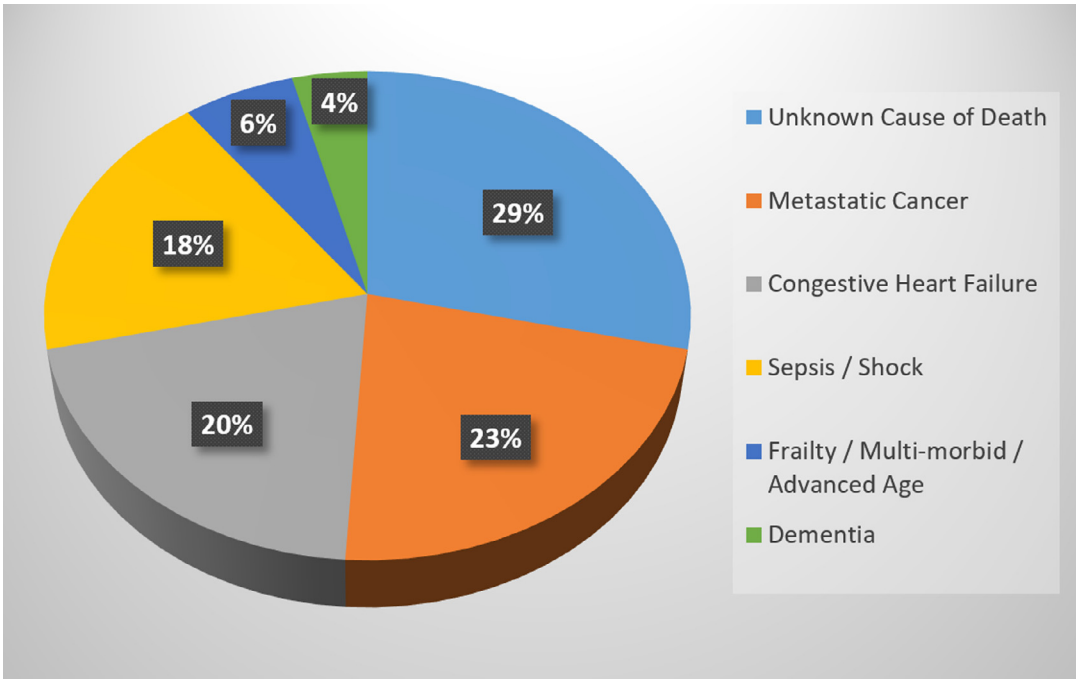

Figure 1. Coexisting terminal diagnosis.

home. No patients had their device deactivated at home (Figure 3). Transient placement of a magnet to temporarily deactivate a device before formal deactivation occurred in 6.1% (3/49) patients.

The KHSC Palliative Care Consult Service was involved in the care of 14.2% (7/49) of patients in this study. All of them had a documented DNR and underwent device deactivation before death as part of their end-of-life care plan. The mean time to device deactivation for patients with Palliative Care consultation after establishment of DNR status was 7 days. Six of those 7 patients had their device deactivated within 1 day of a DNR order being put in place, and the seventh patient had device deactivation 43 days after their DNR order was instituted. Patients without palliative care involvement had their device deactivated a mean of 79 days after their DNR order was instituted.

ICD device therapies were delivered to 42.9% (21/49) of studied patients, with 24.5% (12/49) patients receiving a

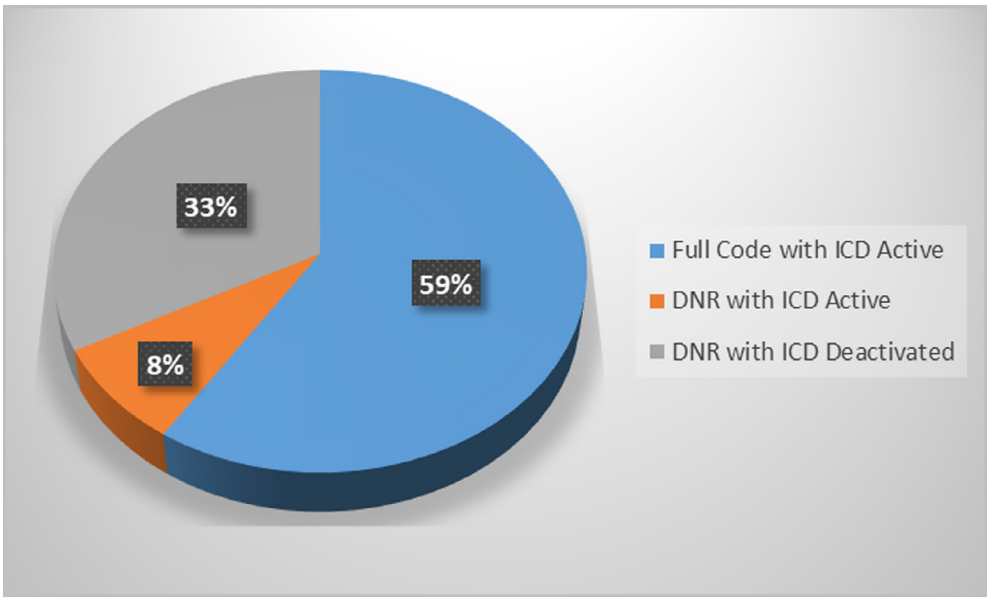

Figure 2. Patient and device status at time of death. Prevalence by percentage of patients who were Full Code, DNR with an active ICD device, or DNR with a deactivated device at the time of death. At the time of death, a patient was either DNR or, by default, Full Code, based on the physician orders and the discussion documentation in the chart. A further subset of patients was identified who were documented DNR but who had not undergone device deactivation at the time of death and therefore died with their ICD's cardioversion/defibrillation therapies active.

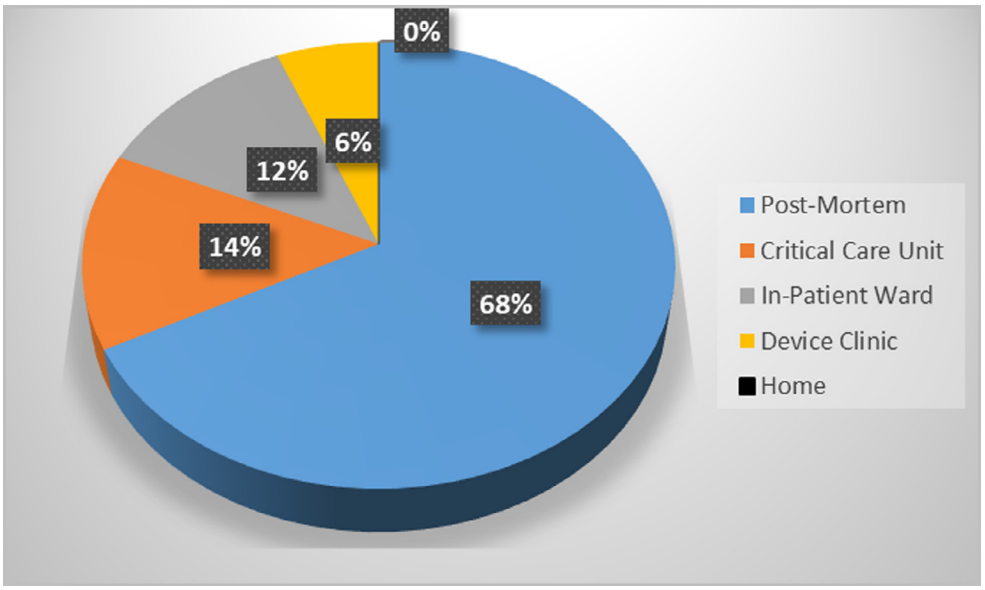

Figure 3. Location of ICD deactivation.

therapy after their terminal diagnosis was established. Antitachycardia pacing was administered to 16.3% (8/49) patients for ventricular tachycardia. At least 1 shock was delivered to 20.4% (10/49) patients; with 18.4% of patients (9/49) receiving defibrillation therapy in the last month of life. Two patients with DNR orders in place received a shock from an active ICD device. In both patients that shock prompted recognition that a functioning device was present and led to formal deactivation of the device shortly after.

Discussion

To our knowledge, this is the first study done to assess the process of device deactivation at a Canadian tertiary care center for patients who have a known terminal diagnosis with an active ICD in situ. We found that only one-third of patients received ICD cardioversion/defibrillation therapy deactivation as part of their end-of-life care. This "deactivation rate" is in keeping with previous literature.[2]

We found that 42.9% of patients received therapy from their device in the year before death, with 24.5% of patients receiving therapy after their terminal diagnosis was established. Almost 20% of patients received a shock within the month before their death, also consistent with previous literature.[13] In many cases, these shocks prompted recognition of an active device, followed by discussions regarding ICD deactivation, culminating in formal device deactivation.

It is estimated that over 140,000 devices capable of defibrillation will be implanted in the United States in 2019 and approximately 800,000 Americans already have one in place.[14] This suggests that there may be thousands of active devices in patients approaching the end of life in the United States alone. These active devices put patients at risk of receiving a painful, and often unwanted, shock during the last months of their life. ICD deactivation may be requested by a patient for any reason, and is an ethical option for patients who do not wish to prolong suffering at the end of life.[15–18]

In our study, patients with a terminal diagnosis had an active device that went undiscussed for an average of 13 months before a discussion leading to formal device deactivation. The Heart Rhythm Society recommends that "discussions about deactivation should begin at the time of implantation as part of the informed consent process" and notes that "these conversations then change over time as the patient's disease progresses."[19] Despite these Heart Rhythm Society recommendations, only about 5% of surveyed patients reported discussing device deactivation with a clinician.[20] This is contrasted by another survey wherein 78.8% of responding physicians claimed that they "were comfortable" with deactivation discussions and that 34.8% of physicians "routinely discussed" device deactivation with their patients.[21]

The reasons surrounding this apparent discrepancy are unclear; it may be that clinicians are uncomfortable discussing end-of-life scenarios with their patients and may defer those discussions until death is more foreseeable and imminent.[13] It is also possible that an active device may not be identified by clinicians or there may be a lack of awareness of how to deactivate the device formally or even during an emergency.[6] Other clinicians may feel ill equipped to discuss device deactivation and prefer that the patient be referred back to the electrophysiologist who implanted the device to have that discussion.[22] It has been proven that delaying or deferring these discussions opens patients up to the risk of receiving painful and unwanted shocks at the end of life.[6,23,24] Our study reaffirms those findings; with approximately 1 in 5 studied patients who had both an ICD and a terminal illness receiving shocks in the last month of life. It is still unclear from the literature precisely when to propose device deactivation to a patient. We propose that, at a minimum, active ICDs should be recognized and discussed by clinicians when a patient opts to become DNR due to their advancing disease.

Palliative care consultation was beneficial for those patients who had active ICDs in situ and a coexisting terminal diagnosis. All patients identified as having palliative care supports in place had documented goals of care discussions that addressed their active ICD device and underwent device deactivation a mean of 7 days after their DNR order was in put in place. In contrast, patients without palliative care involvement had their device deactivated a mean of 79 days after a DNR order was instituted. These data suggest that palliative care specialist team involvement for patients may increase the likelihood that an ICD is identified, discussed, and subsequently deactivated. This would reduce the patient's risk of receiving a painful shock at the end of life.

This study was retrospective in nature and may therefore present data that is inherently biased. The number of patients was small and some charts were incomplete; therefore, there may have been data points that were not captured by this chart review process.

Conclusions

One-third of patients with ICDs and terminal illnesses had their cardioversion/defibrillation therapies deactivated as part of their end-of-life care plan. Approximately 20% of patients received a shock in the last month of life. Having palliative care specialist involvement improved the chances that goals of care discussion, recognition of an active ICD, and a rapid referral for device deactivation occurred.

Further research is needed to identify gaps and appropriate processes and systems to ensure that more patients are provided the opportunity for goals of care discussions and device deactivation as part of their end-of-life care.

Disclosures

The authors have no conflicts of interest to disclose.

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