

Management of Implantable Cardioverter Defibrillators in End-of-Life Care

Nathan E. Goldstein, MD; Rachel Lampert, MD; Elizabeth Bradley, PhD; Joanne Lynn, MD, MA, MS; and Harlan M. Krumholz, MD

Background: Implantable cardioverter defibrillators (ICDs) can prevent premature death from an arrhythmia but may also prolong the dying process and make it more distressing.

Objective: To describe the frequency, timing, and correlates of discussions about deactivating ICDs.

Design: Retrospective cohort study.

Setting: Telephone survey.

Participants: Next of kin of patients with ICDs who died of any cause. Of 136 next of kin contacted, 100 (74%) participated.

Measurements: Incidence of discussions about deactivating ICDs and timing of last shock from ICD.

Results: Next of kin reported that clinicians discussed deactivating the ICD in only 27 of the 100 cases. Most discussions occurred in the last few days of life. Family members reported that 8 patients received a shock from their ICD in the minutes before death.

Limitations: This retrospective survey relied on the reports of next of kin.

Conclusions: Next of kin reported that clinicians discussed deactivating ICDs with few patients. Individuals who choose to receive this device should have the opportunity to choose to discontinue it as death approaches.

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For author affiliations, see end of text.

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Implantable cardioverter defibrillators (ICDs) improve survival by reducing the likelihood of arrhythmic death (1). However, at the end of life, these devices may subject patients to a prolonged, more uncomfortable dying. Since ICD discharges can cause pain and anxiety (1, 2) and avoiding an arrhythmic death may become undesirable in light of the other modes of dying that the patient faces, some patients may prefer to deactivate their ICD near the end of life.

It is unknown, however, how often physicians and patients discuss the management of ICDs at the end of life and the alternative modes of dying. Communication about ICDs at the end of life presents some challenges. Since these devices provide ongoing rhythm monitoring and stand-by intervention, deactivating them may seem to be an act of withdrawing support. In addition, because prognosis in cardiac patients is often ambiguous, even when death is near (3, 4), the opportunity to discuss and decide these issues will often pass before the need to address them becomes obvious.

The goal of our study was to describe the frequency and timing of discussions about deactivating ICDs and evaluate patient factors associated with these discussions. We also sought to characterize the timing of ICD discharges near the end of life. Understanding current patterns can help clinicians improve the quality of care at the end of life for patients with ICDs.

METHODS

Study Sample

Of the patients who had received ICDs at Yale–New Haven Hospital, New Haven, Connecticut, 232 died between 1997 and 2002. To reach our prespecified goal of surveying by telephone the next of kin of 100 of these

patients, we attempted to contact 136 respondents (response rate, 74%). We had incorrect contact information for 16 respondents, 7 respondents declined to participate, and 13 people did not respond. The next of kin who participated in the survey did not differ from those who did not participate in terms of patient age, sex of the patient, sex of the next of kin, or time since patient death ($P > 0.05$). The Human Investigations Committee of Yale University approved the study protocol.

Data Collection

We adapted our survey form from the After-Death Bereaved Family Interview (5, 6), which is a validated instrument to measure the quality of care for dying patients and their families. We retained items from the following sections: demographic characteristics, site of death, and advance care planning. In addition, we asked the next of kin about the patient's mental status and ability to perform activities of daily living (7) in the weeks before death.

We asked questions about the management of the ICD at the end of life, including whether a clinician discussed deactivating the ICD and when the discussion occurred. We also asked when the patient last received a shock from their ICD. To estimate the burden of the patient's illnesses at the end of life, we used a questionnaire-based version (8) of the Charlson comorbidity index (9).

To determine characteristics of the patient's death, we asked the next of kin to provide a brief narrative describing the last weeks of the patient's life. By using previously published definitions (10), we classified the patient's death into 1 of 4 mutually exclusive categories: sudden cardiac, nonsudden cardiac, sudden noncardiac, and nonsudden noncardiac. Inter-rater reliability as measured by concordance, based on review of 20% of surveys by 2 authors, was 95%. We easily resolved disputes by accord.

Context

Implantable cardioverter defibrillators (ICDs) reduce the likelihood of arrhythmic death, but ICD discharges are uncomfortable. Some terminally ill patients may prefer to deactivate their ICDs when maximizing comfort has taken priority over prolonging life.

Contribution

In this survey of the next of kin of 100 patients who died with ICDs in place, only 27 reported that physicians discussed deactivation of the ICD and often did so only in the last few days of life.

Implications

Discussing ICD deactivation may improve the care of patients who are nearing death.

—The Editors

Statistical Analysis

To describe the patient sample and frequency and timing of discussions about deactivating the ICD, we used simple frequencies and proportions. We used the chi-square test and *t*-test to determine associations between patient characteristics and discussions about deactivating the ICD. We used SAS software, version 8.0 (SAS Institute, Inc., Cary, North Carolina), to perform all calculations.

Role of the Funding Source

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RESULTS

Patients had a median age of 76 years, and most patients ($n = 83$) were men (Table 1). Our interviews with the next of kin occurred at a median of 2.3 years after the patient died. The average length of time between death and timing of interview for those patients who did and did not have a discussion about deactivating the ICD was 2.1 and 2.6 years, respectively ($P > 0.05$). The respondents were younger than the patients (median age, 67 years), and most were the spouses of the deceased patients. Patients' ICDs had been in place for a median of 2.3 years. Patients often had a history of several comorbid conditions: 81 patients had heart failure, 22 had stroke, and 6 had metastatic cancer.

The 100 next of kin who were included in the survey reported that discussions about deactivating the ICD occurred in 27 cases. About three quarters of these conversations occurred within the last few days of the patient's life (22% in the last hours, 4% in the last minutes). Among

these 27 discussions, the patient or family decided to deactivate the ICD in 21 cases, and most of the deactivations occurred in the days, hours, or minutes before the patient died.

The only patient characteristics that were statistically associated with having a discussion about deactivating the device were having a do-not-resuscitate order and a higher Charlson comorbidity score (Table 2). We found no statistically significant associations between the patients' or next of kin's demographic characteristics, education, or site of death and the likelihood of having a discussion about deactivating the device (data not shown). We found no association between patients who had a living will or a health care proxy and conversations about deactivating the ICD.

Of the 100 patients, the next of kin reported that 27 patients received a shock in the last month of their life; 8 (30%) of these patients received this shock in the last minutes of life. Of these 27 patients, 9 subsequently had discussions about deactivating the ICD and 6 chose to have their device deactivated. As illustrated by the following

Table 1. Description of Study Sample*

Characteristic	Value
Patients	
Median age (range), y	76.2 (49–91)
Men, <i>n</i>	83
Marital status at time of death, <i>n</i>	
Married	74
Widowed	16
Divorced	7
Never married	3
Race, <i>n</i>	
White	96
Black	4
Median time since death (range)	2.3 y (48 d–4.6 y)
Median time that patient had ICD (range)	2.3 y (4 d–12.5 y)
Mean Charlson comorbidity score at time of death \pm SD	4 \pm 2.4
Classification of patient's death, <i>n</i>	
Sudden cardiac	9
Nonsudden cardiac	51
Sudden noncardiac	4
Nonsudden noncardiac	36
Site of death, <i>n</i>	
At home	22
In hospital	67
Nursing home or long-term care	10
Inpatient hospice	1
Respondents	
Median age (range), y	67 (27–88)
Men, <i>n</i>	18
Relation to patient, <i>n</i>	
Spouse	57
Child	30
Daughter- or son-in-law	5
Sibling	5
Other relative	1
Friend	2

* All *n* values are also percentages, given the total sample ($n = 100$).

quotations, the next of kin found it distressing to witness the patient being shocked at the end of life:

Every 20 minutes, he would [get a shock and get] jolted awake. Meanwhile he was on morphine. . . . I saw this pattern . . . he was waking up from like a really bad dream type of thing . . . and he would say a word or something, and after 20 seconds he would be unconscious again.

His [defibrillator] kept going off. . . . It went off 12 times in 1 night. . . . He went in and they looked at it. . . . They said they adjusted it and they sent him back home. The next day we had to take him back because it was happening [again]. . . . It kept going off and it wouldn't stop going off.

DISCUSSION

In our telephone survey of the next of kin of deceased patients with ICDs, we found a strikingly low rate of discussions about deactivating the devices near the end of life. Conversations about deactivation, as well as the actual turning off of the device, occurred not as decisions planned well in advance of the patient's death but as reactions to distress in the days, hours, or minutes before the patient died.

Discussion about deactivating ICDs at the end of life may have been limited because such conversations may seem out of context to both clinicians and patients. Before implanting an ICD, clinicians explain that these devices will stave off sudden death, which seems desirable. When the patient later is living with fatal illness, the physician must explain that death from an arrhythmia may be a better mode of dying than the patient faces from their other fatal conditions and that repeated firing of the device may be disturbing to patient and family as life comes to a close.

Even among patients with do-not-resuscitate orders, discussions about deactivating the ICD occurred in fewer than 45% of the cases. Discussions about whether to attempt resuscitation commonly include consideration of external shocks (11, 12). Although cardiopulmonary resuscitation and shocks from an ICD differ in both invasiveness and likelihood of returning to the previous functional state, a conversation about resuscitation preferences might be an opportunity to also discuss deactivating an ICD.

Our results support the growing importance of both patient-centered care (13) and improving care for patients with ICDs who are near the end of life (14, 15). By discussing the option of deactivating an ICD, physicians encourage shared decision making and grant patients control over their health care choices (13). Although raising awareness of this issue among clinicians may precipitate discussions, reliable performance requires system-based changes (15). For example, the forms used to document do-not-resuscitate orders might require clinicians to address the issue of deactivating ICDs.

Interpreting our findings requires consideration of cer-

Table 2. Associations between Patient Characteristics and ICD Discussions*

Characteristic	Patients Having Discussion about Deactivating, n (%) [95% CI for Proportion]
Patient's mental state in weeks before death	
Awake and always alert	13 (24 [13–37])
Confused sometimes	9 (35 [17–56])
Confused most times, asleep, or unconscious	5 (36 [13–65])
Patient's ability to perform activities of daily living in weeks before death	
All of the time	6 (29 [11–52])
Some of the time	14 (27 [16–42])
None of the time	7 (28 [12–49])
Patient had advance directive†	
Yes	17 (31 [19–45])
No	10 (26 [13–43])
Patient had DNR order‡	
Yes	21 (45 [30–60])
No	6 (13 [5–27])
Classification of nature of patient's death	
Sudden (cardiac or noncardiac)	1 (8 [0.2–40])
Nonsudden (cardiac or noncardiac)	26 (31 [21–38])
Mean Charlson comorbidity scores ± SD‡	
Patients with ICD discussion (n = 27)	4.9 ± 2.3 [4.0–5.8]
Patients without ICD discussion (n = 70)	3.8 ± 2.4 [3.2–4.3]

* Total sample includes 97 patients because 3 next of kin did not know whether deactivating the ICD was ever discussed. For some characteristics, the number may be smaller because the next of kin could not answer the question about a specific patient characteristic (for example, 4 respondents said they did not know whether the patient had an advance directive). DNR = do not resuscitate; ICD = implantable cardioverter defibrillator.

† Advance directive includes either health care proxy or living will.

‡ $P < 0.05$.

tain limitations. First, our survey relied on the memory of the next of kin. After-death interviews have previously provided valid information about the patient's functional status, communication with clinicians, and awareness of dying (16–18). Furthermore, while the mean length of time between the patient's death and next of kin's interview was approximately 2 years, few respondents answered that they did not remember whether deactivating the ICD had been discussed. In addition, our study sample came from 1 university medical center. Whether these findings apply to other types or locations of medical centers requires further investigation.

In conclusion, we found that clinicians rarely discuss deactivating ICDs with patients, even those patients who are perceived to be near death or those who had previously expressed a desire to limit life-prolonging therapy. As the indications for these devices continue to expand and more devices are implanted (19, 20), the challenges of whether and when to deactivate ICDs will become more pressing.

We encourage professional groups to incorporate consideration of deactivation in “best practice guidelines” to ensure that patients who receive this life-prolonging device can also live out the end of life in accord with their preferences.

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Requests for Single Reprints: Nathan E. Goldstein, MD, Department of Geriatrics, Mount Sinai Medical Center, Box 1070, One Gustave L. Levy Place, New York, NY 10029; e-mail, nathan.goldstein@mssm.edu.

Current author addresses and author contributions are available at www.annals.org.

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Current Author Addresses: Dr. Goldstein: Brookdale Department of Geriatrics, Box 1070, Mount Sinai Medical Center, One Gustave L. Levy Place, New York, NY 10029.

Dr. Lampert: Section of Cardiovascular Medicine, Yale University School of Medicine, 333 Cedar Street, PO Box 208017, New Haven, CT 06510.

Dr. Bradley: Yale School of Public Health, 60 College Street, PO Box 208034, New Haven, CT 06520.

Dr. Lynn: The Washington Home Center for Palliative Care Studies, 3720 Upton Street, NW, Washington, DC 20016.

Dr. Krumholz: Clinical Scholars Program, Yale University School of Medicine, 333 Cedar Street, PO Box 208025, New Haven, CT 06520-8025.

Author Contributions: Conception and design: N.E. Goldstein, R. Lampert, J. Lynn, H.M. Krumholz.

Analysis and interpretation of the data: N.E. Goldstein, R. Lampert, E. Bradley, J. Lynn, H.M. Krumholz.

Drafting of the article: N.E. Goldstein.

Critical revision of the article for important intellectual content: N.E. Goldstein, R. Lampert, E. Bradley, J. Lynn, H.M. Krumholz.

Final approval of the article: N.E. Goldstein, R. Lampert, E. Bradley, J. Lynn, H.M. Krumholz.

Provision of study materials or patients: R. Lampert.

Statistical expertise: N.E. Goldstein.

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