Brief Communication: Management of Implantable Cardioverter-Defibrillators in Hospice: A Nationwide Survey

Nathan Goldstein, MD; Melissa Carlson, MBA, PhD; Elayne Livote, MPH, MS, MA; and Jean S. Kutner, MD, MSPH

Background: Communication about the deactivation of implantable cardioverter-defibrillators (ICDs) in patients near the end of life is rare.

Objective: To determine whether hospices are admitting patients with ICDs, whether such patients are receiving shocks, and how hospices manage ICDs.

Design: Cross-sectional survey.

Setting: Randomly selected hospice facilities.

Participants: 900 hospices, 414 of which responded fully.

Measurements: Frequency of admission of patients with ICDs, frequency with which patients received shocks, existence of ICD deactivation policies, and frequency of deactivation.

Results: 97% of hospices admitted patients with ICDs, and 58% reported that in the past year, a patient had been shocked. Only 10% of hospices had a policy that addressed deactivation. On average, 42% (95% CI, 37% to 48%) of patients with ICDs had the shocking function deactivated.

Limitation: The study relied on the knowledge of hospice administrators.

Conclusion: Hospices are admitting patients with ICDs, and patients are being shocked at the end of life. Ensuring that hospices have policies in place to address deactivation may improve the care for patients with these devices. The authors provide a sample deactivation policy (available at www.annals.org).

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The indications for implantable cardioverter-defibrillators (ICDs) have recently been expanded (1, 2). Because shocks from an ICD are painful and anxiety-provoking (3, 4), some patients may choose to have the shocking function deactivated near the end of life. Conversations about deactivation are complicated and rare (5, 6), however, and patients may not understand the role the device plays in their end-of-life care (7).

Hospices have long been leaders in caring for patients with advanced disease. Patients admitted to hospice must have a life expectancy of 6 months or less and agree to forgo life-prolonging treatment. A discussion about ICD management is therefore appropriate for a patient with an ICD who is receiving hospice care. However, no systematic examination of management for patients receiving hospice care has been performed.

Our objectives were to determine the frequency with which hospices are admitting patients with ICDs, the frequency with which such patients are receiving shocks, and the processes that hospices use to care for patients with ICDs.

Methods

We received a list of 3750 hospices from the National Hospice and Palliative Care Organization, whose membership includes more than 80% of U.S. hospices (8). From this list, we generated a stratified random sample of 100 hospices from each of the 9 U.S. Census regions. To account for the unequal probability of hospice selection by region, we included a sampling weight proportional to the inverse of the probability of a hospice being chosen by using SAS, version 9.1.3 (SAS Institute, Cary, North Carolina).

We created a novel survey instrument based on our previous work (6, 7). The survey asked how many patients with active ICDs had been admitted and gave respondents a range of choices. It then asked whether any of the patients had been shocked in the past year (yes or no) and whether any had received multiple shocks (yes or no). Next, the survey asked whether the hospice intake forms had an item to identify patients with ICDs (yes or no), whether the hospice had a formal deactivation policy (yes or no), what percentage of patients had their device deactivated while receiving hospice care (open-ended), and whether the hospice had a strong magnet on hand for emergency deactivation (yes or no). (Questions about ICD deactivation were clearly stated as referring only to the shocking function.) We asked hospices with formal policies to submit a copy of their policy.

We then sent the survey to the Scientific Advisory Committee of the Population-Based Palliative Care Research Network (www.uchsc.edu/popcrn). The Advisory Committee provided feedback on survey readability, ease...
Patients with implantable cardioverter-defibrillators (ICDs) are being admitted to hospice care, and little is known about how these patients are managed.

The investigators surveyed a nationally representative sample of 900 hospices, of which 414 responded fully. Of these, 97% admitted patients with ICDs and 58% reported that at least 1 patient had been shocked in the past year. Forty-two percent of patients with ICDs had the shocking function deactivated.

The study relied on the knowledge of hospice administrators.

Hospices should develop policies about ICD deactivation to avoid shocks at the end of life.

—The Editors

of use, and validity. We then pilot-tested the survey with several clinicians. Because the study did not collect patient data, it was exempt from review by Mount Sinai School of Medicine’s institutional review board.

We mailed the survey to all selected hospices. Respondents could either fax back the paper version or complete an identical version online. We used a series of incentives, which included a pen and a $2 bill. We called nonresponding hospices to encourage participation.

We present results relating to response rate and analysis of deactivation policies as actual (unweighted) numbers and all other results as weighted percentages. We used the chi-square and tests for bivariate analyses. When hospices answered “don’t know” to a yes-or-no question, we performed a sensitivity analysis in which we assigned these responses as first “no” and then “yes” to determine the potential range of possible responses.

We reviewed the submitted ICD policies (interrater reliability, 96%) for 3 generally accepted necessary criteria (9, 10): a prompt to identify patients with ICDs, discussion of the benefits and burdens of the device as they relate to the patient’s illness, and instructions on how to reprogram the device. In addition, we examined the policies to determine whether they discussed the ethical basis for deactivation, what to do if a patient could not travel, and a process that outlined the use of a magnet in an emergency setting. These last criteria have been identified as being important (although not essential) elements of a deactivation policy (10).

Role of the Funding Source

This study was funded by the National Institute of Aging and the National Institute of Nursing Research. The funding sources had no role in the study design, data collection, or manuscript preparation.

RESULTS

After accounting for the 41 hospices for which we had incorrect contact information and the 24 that no longer operated as a hospice, we reduced the denominator to 835. We treated the 62 hospices that indicated that they did not admit patients with ICDs but did not provide further information as refusals, as described elsewhere (11). We received completed surveys from 414 hospices, a 50% response rate. We found no evidence that response rates differed by census region (chi-square, 11.2; $P = 0.20$). The Table shows the hospices’ characteristics.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Result</th>
<th>Sensitivity Analyses†</th>
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<tbody>
<tr>
<td>Ownership type, %</td>
<td></td>
<td></td>
</tr>
<tr>
<td>For profit</td>
<td>25</td>
<td>–</td>
</tr>
<tr>
<td>Not for profit</td>
<td>72</td>
<td>–</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td>–</td>
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<tr>
<td>Unknown</td>
<td>1</td>
<td>–</td>
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<tr>
<td>Mean daily census (±SE), n</td>
<td>116.5 ± 10.6</td>
<td>–</td>
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<tr>
<td>Mean length of stay (±SE), d</td>
<td>62.3 ± 2.0</td>
<td>–</td>
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<tr>
<td>Mean patients with heart disease as a hospice-qualifying diagnosis (±SE), %</td>
<td>15.3 ± 0.6</td>
<td>–</td>
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<tr>
<td>Facilities that will admit patients with active ICDs (95% CI), %†</td>
<td>97 (96–99)</td>
<td>89–97</td>
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<tr>
<td>Patients with an active ICD admitted to hospice in the past year, %</td>
<td>0</td>
<td>15 –</td>
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<tr>
<td>1–10</td>
<td>76</td>
<td>–</td>
</tr>
<tr>
<td>11–25</td>
<td>6</td>
<td>–</td>
</tr>
<tr>
<td>26–50</td>
<td>2</td>
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<tr>
<td>51–100</td>
<td>1</td>
<td>–</td>
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<tr>
<td>&gt;100</td>
<td>0</td>
<td>–</td>
</tr>
<tr>
<td>Facilities that ask on intake form whether patient has an ICD (95% CI), %†</td>
<td>20 (16–24)</td>
<td>19–21</td>
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<td>Hospices with a written policy for deactivating ICDs (95% CI), %†</td>
<td>10 (7–13)</td>
<td>10–12</td>
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<tr>
<td>≥1 patient shocked by ICD at hospice (95% CI), %†</td>
<td>58 (53–64)</td>
<td>45–68</td>
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<td>≥1 patient shocked multiple times by ICD at hospice (95% CI), %†</td>
<td>40 (34–47)</td>
<td>25–59</td>
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<tr>
<td>ICD deactivation method, %‡</td>
<td></td>
<td></td>
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<tr>
<td>Patient sent to clinic</td>
<td>34</td>
<td>–</td>
</tr>
<tr>
<td>Member of hospice team turns off device</td>
<td>14</td>
<td>–</td>
</tr>
<tr>
<td>Nonhospice health care provider comes to hospice or home to deactivate device</td>
<td>31</td>
<td>–</td>
</tr>
<tr>
<td>Representative from device manufacturer comes to hospice or home to deactivate device</td>
<td>47</td>
<td>–</td>
</tr>
<tr>
<td>Hospice has magnet to deactivate device (95% CI)†</td>
<td>25 (20–29)</td>
<td>24–28</td>
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<tr>
<td>Of hospices with magnet, staff receive special training in its use (95% CI)†</td>
<td>64 (53–76)</td>
<td>60–66</td>
</tr>
</tbody>
</table>

ICD = implantable cardioverter-defibrillator.

* Weighted data.

† Results of a sensitivity analysis to determine the range of potential responses for facilities that answered “don’t know.”

‡ Hospices could choose more than one response.

Table. Characteristics of Hospices and Management Practices Relating to ICDs*
Almost all hospices (97%) admitted patients with active ICDs. In the past year, 76% of hospices admitted between 1 and 10 patients with an active ICD. Fifty-eight percent of hospices reported that at least 1 person was shocked in the last year, and 40% of those reported that at least 1 patient had received multiple shocks during a single episode.

Twenty percent of hospices had a question on their intake forms to identify patients with ICDs, and 10% had a deactivation policy. Hospices with a question on their intake forms were more likely to have a deactivation policy (odds ratio, 4.6 [95% CI, 2.3 to 9.2]). Twenty-five percent had a strong magnet available to deactivate an ICD; of these, 64% provided training in its use.

Of patients with active devices, an average of 42% (CI, 37% to 48%) had the shocking function deactivated while receiving hospice care. Hospices with a deactivation policy had a higher mean percentage of patients who had their devices deactivated than hospices with no such policy (73% vs. 38%; P < 0.001).

Fifteen hospices provided copies of their deactivation policies. In a content analysis, 11 had a section that prompted device identification, 15 discussed informed consent in relation to deactivation, and 14 outlined the steps to reprogram the device. In addition, 9 discussed the ethical basis for deactivation, 9 addressed what should be done if the patient could not travel, and 7 addressed emergency use of a magnet. No policy required deactivation. We synthesized elements of submitted policies to create a sample policy that contains all of the essential elements (Appendix, available at www.annals.org).

**Discussion**

We found that hospices were admitting patients with active ICDs and that patients with these devices were being shocked near the end of life. Fewer than half of patients had their devices deactivated while receiving hospice care, and a hospice policy that addressed deactivation was associated with a higher percentage of device deactivations.

Improvements in models of care for patients with ICDs and advanced disease are needed. Having a question on the hospice intake form is strongly related to having a deactivation policy, but most facilities have neither. Our results do not establish a causal relationship between having a policy and having more devices deactivated, but the relationship is intriguing, and further study is needed. By providing the sample policy, we hope to facilitate quality improvement for hospices. Our objective with the sample policy is for hospices to adapt it to their own circumstances to improve the quality of care for patients and their families.

Our sample policy is a combination of the best elements of the policies we received. We caution people who use the sample policy to remember that ICDs are complex devices that may be multifunctional in many cases. A clear understanding of these devices is important to ensure the highest-quality conversations with patients and their families. Hospices must create relationships with local electrophysiologists and representatives from device manufacturing companies to ensure that patients—especially those who cannot leave their place of residence—can have their devices reprogrammed. Willingness of nonhospice clinicians or manufacturer representatives to do home visits may vary; thus, the implications of device deactivation are important not only for hospices but also for any clinician who deals with a patient with an ICD.

To our knowledge, ours is the first nationwide study to examine the management of ICDs in patients receiving hospice care. Our study has limitations. First, we relied on the knowledge of hospice administrators and did not directly verify the data that the hospices provided; however, we did ask the survey recipients to work collaboratively with other team members when responding. Second, our response rate was low but similar to or better than that of other studies that examined practices in end-of-life care (12–14), and response rates did not vary by region. Finally, we conducted our survey at the level of the hospice and collected no information about individual patients. Future work will need to determine how patient-level factors relate to ICD deactivation practices.

In conclusion, hospices enroll patients with active ICDs, and patients are shocked near the end of life. These data show an association between having a deactivation policy and a higher percentage of patients with deactivated ICDs. We hope that by providing a sample policy, hospices will engage in quality improvement activities to improve outcomes for patients with ICDs and their families.
Reproducible Research Statement: Study protocol, statistical code, and data set: Available from Dr. Goldstein (e-mail, Nathan.Goldstein@mssm.edu).

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

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

References
APPENDIX: SAMPLE ICD DEACTIVATION POLICY

This policy is a synthesis of actual policies submitted by responding hospices. It provides the core elements that should be included in a policy that addresses the management of these devices for patients receiving hospice care. It has not been piloted and should be adapted by hospices after they have identified community partners who will assist with the reprogramming of patients’ devices.

Ethical Rationale for Deactivation

Implantable cardioverter-defibrillators are often multifunctional devices that are programmed to meet an individual patient’s cardiac needs. These devices are designed to terminate potentially life-threatening arrhythmias in patients, and one way that they do this is to deliver electrical shocks to the heart. Unlike other treatments these devices may deliver to correct arrhythmias, the patient may experience pain or discomfort when the ICD discharges. That an ICD is present does not automatically mean that it will fire as death approaches. Deactivation of the shocking function is not a requirement for admission to hospice but may be in line with the hospice care goal of preserving quality of life during the dying process. Defibrillators are subject to the same ethical and clinical considerations as any other medical treatment. Similarly, ICDs are subject to an analysis of potential benefits and burdens, and patients or their surrogates have the right to accept or decline its interventions. These should not be isolated decisions but should instead be made in the context of the patient’s larger goals of care.

Identification of Device

At the time of evaluation and admission to hospice (regardless of the setting in which care is delivered), all patients or their families will be queried about the presence of a pacemaker or ICD. On physical examination, the chest wall of each patient should be checked for the presence of a cardiac device (devices are usually placed underneath the clavicle and may be visible or palpable). If a device is identified, the patient or his or her family should be asked whether the patient has the card that was provided at implantation, to aid in determining the nature of the device. If this card cannot be located, the hospice nurse should contact the patient’s primary care physician or cardiologist to determine the nature of the device.

Informed Consent Discussion About Device Deactivation

After an ICD has been identified, the hospice nurse should engage in an informed consent discussion with the patient, family, or surrogate about the potential benefits and burdens of the device at this point in the patient’s illness. To make a truly informed choice about whether to deactivate the shocking function, the nurse should emphasize the following points during the discussion:

1. Leaving the defibrillation function on could potentially cause the patient to experience pain if the device delivers shocks near the end of life.
2. Turning off the shocking function means the device will not be able to provide all of the available methods of life-saving therapy in the event of a potentially fatal heart rhythm. Leaving the shocking function active does not guarantee, however, that the heart will return to a normal pattern of beating after an arrhythmia.
3. Turning off the ICD will not cause death.
4. Turning off the ICD will not be painful, nor will a patient’s death be more painful if it is turned off.
5. Decisions about deactivating a pacemaker are often made separately from the decision to turn off a defibrillator, and they depend on the indication for the pacemaker and the patient’s underlying intrinsic cardiac rhythm. Both are justifiable on ethical grounds, however, depending on the patient’s overall goals of care. Deactivating a pacemaker may result in changes in a patient’s symptoms. Consultation with a cardiologist or electrophysiologist before deactivation is often advisable to ensure that appropriate treatments are readily available if the pacemaker is deactivated.

Process for Reprogramming the ICD

If a decision has been made to deactivate the shocking function of the ICD, the hospice nurse will inform the medical director that the decision has been made to reprogram the device so it will no longer deliver shocks.

Note: Reprogramming an ICD in this manner will stop it from ever delivering shocks. Placing a magnet over the ICD will stop it from sensing the rhythm and delivering a shock, but only while the magnet is physically present over the device.

If the patient is ambulatory, the nurse will contact the patient’s cardiologist or electrophysiologist to arrange for the patient to come to the office to deactivate the shocking function.

If the patient cannot leave his or her place of residence, then the hospice nurse will develop a plan with the attending physician for reprogramming the patient’s ICD, which may include one of the following processes:

1. The patient’s cardiologist or electrophysiologist or a member of his or her team will be contacted to come to the patient’s place of residence to reprogram the device.
2. A member of the hospice team with special training in the deactivation of ICDs will arrange to borrow the equipment (sim-
ilar to a small laptop computer) from the cardiologist or electrophysiologist and bring it to the patient’s place of residence to reprogram the device. Equipment may be manufacturer-specific, so this team member must know which manufacturer made the patient’s ICD.

3. A representative from the device manufacturer, after appropriate consultation with the hospice medical director or the patient’s cardiologist or electrophysiologist, will come to the patient’s place of residence to reprogram the ICD.

If the patient is not ambulatory, the hospice nurse will be present in the place of residence during the reprogramming process to provide emotional support to the patient, family, and surrogate.

**Process for Deactivation of an ICD in an Emergent Scenario**

If the decision is for the shocking function of the ICD to remain active, a magnet designed for cardiac devices should be left in the patient’s place of residence in the event of an emergent scenario in which the patient is being repeatedly shocked. It should be explained to the family that if a patient is receiving repeated shocks from the ICD, then placing the magnet over the device will stop it from sensing the cardiac arrhythmia. The magnet will need to be taped in place because it only stops the ICD from sensing. (An ICD that does not sense will not deliver treatments.) Once the magnet is removed, the ICD will again begin sensing and may again deliver shocks.* The magnet is heavy and may not be comfortable if left in place for an extended period. If the family is not comfortable performing this procedure themselves, the magnet should still be left in the place of residence so that a hospice nurse who arrives in an emergent situation will have the necessary tools to suspend the shocking function of the device.

**Postmortem Care**

After a patient has died, the ICD will not deliver a shock. If a magnet has been taped to the chest, it can be removed as soon as a nurse has verified that the patient no longer has cardiac function. If the body is to be cremated, the funeral director should be notified of the presence of an ICD, because incinerating the battery can cause it to explode.

* At the time this protocol was written, one ICD on the market would be permanently reprogrammed to completely deactivate its shocking function when placed in the presence of a magnet for a brief period. If one is not sure of the exact specifications of a patient’s ICD, the best practice is to keep the magnet in place.