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Management of Implantable Defibrillators in Hospice

Nathan Goldstein, MD[1,2], **Melissa Carlson, MBA, PhD**[1], **Elayne Livote, MPH, MS, MA**[2], and **Jean S. Kutner, MD, MSPH**[3]

[1] Lilian and Benjamin Hertzberg Palliative Care Institute of the Brookdale Department of Geriatrics and Adult Development, Mount Sinai School of Medicine, New York, NY

[2] Geriatrics Research, Education, and Clinical Care Center, James J. Peters Veterans Affairs Medical Center, Bronx, NY

[3] Division of General Internal Medicine, University of Colorado Denver School of Medicine, Aurora, CO

Abstract

Background—Communication about deactivation of ICDs in patients near the end of life is rare.

Objectives—To determine if hospices are admitting ICD patients, if hospice patients are receiving shocks, and how hospices manage ICDs.

Design—Cross-sectional survey.

Setting—Randomly selected hospice facilities

Participants—900 hospices were surveyed. A total of 414 hospices responded.

Measurements—Frequency of admission of ICD patients, frequency of patients receiving shocks, existence of deactivation policies, and frequency of deactivation.

Results—97% of hospices admit patients with ICDs. 58% reported that in the last year a patient had been shocked. Only 10% of hospices had a policy which addressed deactivation. On average, 42% (SE 2.9) of patients with ICDs have the shocking function deactivated. A sample deactivation policy is available as a web-only appendix.

Limitations—The study relied on the knowledge of hospice administrators.

Conclusions—Hospices are admitting patients with ICDs, and patients are being shocked at the end of life. Assuring that hospices have policies in place to address deactivation may improve the care for patients with these devices.

Introduction

There has recently been significant expansions in the indications for Implantable Cardioverter Defibrillators (ICDs).(1, 2) Because shocks from an ICD are painful and anxiety provoking,

Address all correspondence/requests for reprints to: Dr. Nathan Goldstein Mount Sinai School of Medicine Department of Geriatrics, Box 1070 One Gustave Levy Place New York, NY 10029 Phone: 212-241-1446 Fax: 212-860-9737 Nathan.Goldstein@mssm.edu.

(3, 4) at the end of life some patients may choose to have the shocking function deactivated. Deactivation conversations are complicated and rare (5, 6) and patients may not understand the role the device plays in their end-of-life care.(7)

Hospices have long been a leader in caring for patients with advanced disease. Patients admitted to hospice must have a prognosis of six months or less and agree to forego life-prolonging treatment. As such, a discussion about defibrillator management is appropriate for hospice patients with an ICD. However, there has been no systematic examination of the management of ICDs for patients on hospice.

The objectives of this study were to determine the frequency with which hospices are admitting ICD patients, the frequency with which hospice patients are receiving shocks, and the processes hospices use to care for ICD patients.

Methods

We received a list of 3750 hospices from the National Hospice and Palliative Care Organization, whose membership includes over 80% of U.S. hospices.(8) From this list, we generated a stratified random sample of 100 hospices from each of the 9 US 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 using SAS/STAT® Version 9.1.3 (9).

Based on our previous work, (6, 7) we created a novel survey instrument. The survey asked how many patients with active ICDs had been admitted, and respondents were given a range of choices. The survey then asked if any of the patients had been shocked (yes/no) and if any had ever received multiple shocks (yes/no). The survey prompted for the time period of these responses to be “in the last year.” Next, the survey asked if there was an item on the hospice intake forms to identify ICD patients (yes/no), if the hospice had a formal deactivation policy (yes/no), what percent of patients had their device deactivated while on hospice (open-ended), and if there was a strong magnet on hand for emergency deactivation (yes/no). (It was clearly stated that questions about device deactivation referred only to the shocking function.) Hospices with formal policies were asked to submit a copy.

We then sent the survey to the Scientific Advisory Committee of the Population-based Palliative Care Research Network.(10) The Advisory Committee provided feedback on survey readability, ease of use, and validity. The survey was next pilot tested with several clinicians. Since the study did not collect patient data, it was exempt from review according to Mount Sinai's Institutional Review Board.

We mailed the survey to all selected hospices, and respondents could either fax back the paper version or complete an identical version online. We used a series of incentives, including a pen and a $2 bill. Non-responding hospices were called to encourage participation.

Results relating to response rate and analysis of deactivation policies are presented as actual (unweighted) numbers. All other results are reported as weighted percentages. Chi-square and t-test were used for bivariate analyses. When hospices answered “don't know” to a yes/no question, we performed a sensitivity analysis where we assigned all of the “don't know” responses as both “no” and then “yes” to determine the potential range of responses that might be possible.

We (NG, MC) reviewed the submitted ICD policies (inter-rater reliability was 96%) for the following generally accepted necessary criteria (11, 12): 1) prompt to identify patients with ICDs; 2) discussion of the benefits/burdens of the device as they relate to the patient's illness;

and 3) instructions as to how to have the device re-programmed. In addition, we examined the policies to determine if they discussed the ethical basis for deactivation, what to do if a patient could not travel, and a process outlining 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.(12)

Results

After accounting for those hospices for which we had incorrect contact information (n=41) or which no longer operated as a hospice (n=24), the denominator was reduced to 835. The 62 hospices who told us they have not admitted ICD patients but declined to provide any further information were treated as refusals, as has been previously described.(13) We received completed surveys from 414 hospices, a 50% response rate. Response rates did not differ by census regions (χ^2=11.2; P=0.20). The table shows the hospices' characteristics.

Almost all hospices (97%) would admit patients with active ICDs. In the last year, 76% of hospices admitted between 1-10 patients with an active ICD. 58% of hospices reported that at least one person was shocked in the last year, and 40% of those reported that at least one patient had received multiple shocks during a single episode.

20% of hospices had a question on their intake forms to identify patients with ICDs, and 10% of hospices 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% confidence interval 2.3-9.2). 25% of hospices had a strong magnet available to deactivate an ICD, and of those 64% provided training in its use.

Of patients with active devices, on average 42% (SD = 2.9) have the shocking function turned off while on hospice. Hospices which have a policy are more likely to have a higher mean percentage of patients have their devices deactivated compared to those without a policy (73% vs. 38%, P<0.001).

Fifteen hospices provided copies of their deactivation policies. In a content analysis, 11 had a section prompting device identification, 15 discussed "informed consent" in relation to deactivation, and 14 outlined the steps to reprogram the device. In addition, 9 discuss the ethical basis for deactivation, 9 addressed what should be done if the patient cannot travel, and 7 addressed the emergency use of a magnet. No policy required deactivation. The authors synthesized elements of submitted policies to create a sample policy that contains all of the essential elements (web-only appendix).

Discussion

We found that hospices were admitting patients with active ICDs and patients with these devices were being shocked near the end of life. Less than half of patients had their devices deactivated during their time on hospice, and having a policy addressing deactivation was associated with a higher percentage of device deactivation.

Improvements in models of care for ICD patients with advanced disease are needed. The strong relationship between having a question on the hospice intake form and having a deactivation policy demonstrates that the two go hand-in-hand, but most facilities have neither. A causal relationship between having a policy and a greater number of devices deactivated cannot be established, but the relationship is intriguing and further study is needed. By writing the sample policy we hope to facilitate quality improvement for hospices. Our objective in providing this sample policy is that hospices will adapt it to their own circumstances to improve the quality of care for patients and their families.

The sample policy proposed is a combination of the "best elements" of the policies the investigators received. It must be remembered that ICDs are complex devices, and in many cases may be multi-functional. A clear understanding of these devices is important to assure the highest quality conversations with patients and their families. Hospices must create relationships with local electrophysiologists and representatives from device manufacturing companies to assure that patients – especially those who cannot leave their place of residence – are able to have their devices re-programmed. Willingness of non-hospice clinicians or manufacturer representatives to do "home visits" may vary, thus the implications of device deactivation are not only important for hospices – but also for any clinician who deals with a patient with an ICD.

This is the first nationwide study examining the management of ICDs in hospice patients. There are limitations that must be considered. First, this study relied on the knowledge of hospice administrators so data provided by the hospices cannot be directly verified; we did, however, ask the recipient to work collaboratively with other team members when responding. Second, our response rate was low, but it is similar to or better than other studies examining practices of end-of-life care, (14¯16) and there was no regional variation in response rates. Finally, the survey was conducted at the level of the hospice, so no information about individual patients was collected. 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 are encouraged to engage in quality improvement activities that will improve outcomes for patients with ICDs and their families.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table

Characteristics of Hospices and Management Practices Relating to Implantable Defibrillators.[1]

Ownership Type (%)	
For Profit	25%
Not-for-Profit	72%
Other	2%
Unknown	1%
Daily Census Mean (SE)	116.5 (10.6)
Length of Stay in Days Mean (SE)	62.3 (2.0)
Percent of Patients with Admitting Diagnosis of heart Disease Mean (SE)	15.3 (0.6)
Facilities that will Admit Patients with Active ICDs[2]	97% (96, 99) [89-97%]
Number of Patients Hospice Admitted with an Active ICD in the Last Year	
0	15%
1-10	76%
11-25	6%
26-50	2%
51-100	1%
>100	0%
Facilities with Question on Intake Form Asking if Patient Has ICD[2]	20% (16, 24) [19-21%]
Hospices with Written Policy for Deactivating ICDs[2]	10% (7, 13) [10-12%]
At Least One Patient at Hospice was Shocked[2]	58% (53, 64) [45-68%]
At Least One Patient at Hospice was Shocked Multiple Times[2]	40% (34, 47) [25-59%]
How are ICDs Deactivated?[3]	
Patient Sent to Clinic	34%
Member of hospice team turns off device	14%
Non-Hospice health care provider comes to hospice/home to deactivate device.	31%
Representative from device manufacturing company come to hospice/home to deactivate device.	47%
Hospice has magnet on hand to deactivate ICD.[2]	25% (20, 29) [24-28%]
Of hospices with magnet, special training is provided to staff in its use.[2]	64% (53, 76) [60-66%]

[1] Weighted data.

[2]Percentages shown in the parenthesis represent the 95% confidence interval for the data. Percentages shown in brackets represent a sensitivity analysis to determine the range of potential responses for those facilities that answered “don't know” to the question. The range was determined by assigning either all “no” or all “yes” answers to those hospices that answered “don't know” to the question.

[3]Hospices could choose more than one response.