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Adverse experiences with implantable defibrillators in Oregon hospices

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Abstract

Background—Implantable cardioverter-defibrillators (ICDs) improve survival in patients at risk for recurrent, sustained ventricular tachycardia or fibrillation. Unless deactivated, ICDs may deliver unwanted shocks to terminally ill patients near the time of death. This study sought to determine the frequency and nature of adverse experiences with ICDs events and what preventative measures the hospice programs had taken.

Method—A mailed survey to all 50 Oregon Hospice Programs in August 2008.

Results—42/50 (84%) programs participated. 36/42 (86%) programs reported having taken care of a patient with an ICD in the preceding four years. The average number of patients with ICDs per program increased from 2.2 (SD 2.5) in 2005 & 2006 to 3.6 (SD 3.7) in 2007 & 2008. Of the 36 programs who had cared for a patient with an ICD, 31 (86%) reported having some kind of adverse experience. These ranged from unwanted shocks delivered (64%), patient/ family distress related to the decision to deactivate the ICD (47%), and time delay in ICD deactivation (42%). Only 16 (38%) programs had policies for managing ICDs and only 19 (43%) routinely screened new patients for ICDs.

Discussion—As patients near the end of their lives, receiving defibrillating shocks may no longer be consistent with their goals of care. Based on the high frequencies of potentially preventable adverse outcomes documented by this study, we propose that hospices routinely screen patients for ICDs and adopt policies to proactively manage them, rather than in response to an adverse event.

Background

Implantable cardioverter-defibrillators (ICDs) are used in patients at risk for recurrent, sustained ventricular tachycardia or fibrillation. ICDs consist of an impulse generator implanted under the skin in the chest or abdomen and one or more tunneled leads positioned inside the heart or on its surface. ICDs include electronics that detect and monitor heart rhythms and can perform overdrive pacing to interrupt ventricular tachycardia, deliver a cardioverting shock if that fails, and deliver a higher voltage defibrillating shock for ventricular fibrillation. Current models can also treat atrial arrhythmias and perform biventricular pacing in patients with congestive heart failure or bradycardia. In terms of deactivation, the pacing and cardioverting/defibrillating functions of ICDs can be

deactivated separately with the proper equipment.¹ ICDs have proven effective in preventing sudden death in patients with known, sustained ventricular tachycardia or fibrillation.^{2,3} Current research is focusing on their prophylactic role for patients who are at risk for ventricular tachycardia or fibrillation.^{4,5,6,7}

In 2005, Medicare expanded reimbursement for the prophylactic use of ICDs for prevention of sudden cardiac death, increasing the potential pool of patients who might benefit from implantation.⁸ It is reported that between three and four million patients are currently eligible for device implantation, with an additional 400,000 eligible each year.⁶ Currently, cardiac disease accounts for approximately twelve percent of hospice diagnoses, second only to cancer.⁹ ICDs and improved cardiac disease management have extended the disease trajectory for many patients with ICDs who are living long enough to develop non-cardiac terminal diagnoses.¹⁰

ICDs may pose a dilemma for patients who are terminally ill and wish to forego cardiopulmonary resuscitation.¹¹ Patients dying of causes other than ventricular tachycardia or fibrillation who develop these arrhythmias may receive shocks that could be painful and distressing to the patient and his or her family. In a study of 100 decedents with ICDs who died of any cause, 27% reported that their family member received a shock in their last month of life, and 8% reported a shock in the last minutes of life.¹² For reference, patients often describe the cardioverting shock as a ‘thump’ in the chest and the defibrillating shock as a ‘kick’ in the chest.¹³ Some patients develop anxiety disorders in response to their fear of being shocked.¹⁴ As patients near the end of their lives, receiving defibrillating shocks may cease to be consistent with their goals of care.^{15,16}

Having heard stories of delays in deactivating ICDs and unwanted shocks in the final hours and days of life from hospice clinicians, we sought to determine what proportion of Oregon hospices had adverse events, the nature of the adverse events, and what preventative measures the hospice programs had taken.

Methods

We developed a written survey asking Oregon hospice programs about specific adverse experiences they might have had in caring for patients with ICDs and whether they had policies designed to prevent such experiences. Most of the questions required a yes or no response. Two open ended questions asked respondents to “describe an example of a memorable patient with an ICD” and to “describe any other policy or approach” the program had for dealing with ICDs. We pilot tested and revised the survey based on feedback from 5 hospice administrators and a group of primary care ‘research in progress’ conference attendees. All hospice programs in Oregon were eligible to participate.

We mailed the survey to hospice administrators using addresses from the Oregon Hospice Association’s registry, available on the World Wide Web in August 2008. The instructions for the survey included informed consent, provided a check box to opt out of the study, and encouraged the administrator to fill out the survey or to assign that task to another hospice employee. To encourage response we included a certificate that could be redeemed for a complimentary book once the survey was returned.

Hospices that did not respond after 3 weeks were sent a second mailing, followed 3 weeks later by a phone call from one of the investigators checking to ensure that the survey was being received by the right person in the organization. The survey’s first page included a unique identifier so that we could keep track of responders—once the survey was returned we removed the first page rendering the survey anonymous.

Data were analyzed using SPSS statistical software package. Tests of significance included Chi square and paired t test. Qualitative responses to open ended questions were examined to identify previously undescribed adverse events or ICD policy approaches to in hospice care. The free text responses were evaluated using qualitative description—a method of choice when straightforward and less interpreted evaluation is desired.¹⁷

Results

Oregon hospice programs were identified using the Oregon Hospice Association's online registry (<http://www.oregonhospice.org/registry.htm>). 42/50 programs responded to the survey (84%), 2 programs declined and 6 had not responded after 2 mailings and phone follow up. Descriptive data for the responding programs are listed in Table 1. Non-participating programs included 6 rural not-for-profit programs and 2 urban proprietary programs. Qualitative review of the 2 open ended questions did not reveal common themes that were unaddressed by the other questions but *did* illustrate how distressing adverse events with ICDs could be for patients, families, and hospice staff. We have included several quotes that highlight issues raised by the quantitative analysis.

ICDs

36/42 (86%) of programs reported having taken care of a patient with an ICD in the past 4 years. The average number of patients with ICDs seen by Oregon hospices has increased over time—from 2.2 (SD 2.5) patients per program for 2005 & 2006 to 3.6 (SD 3.7) patients per program for 2007 & 2008.

Adverse experiences with ICDs

Of the 36 programs who had cared for a patient with an ICD, 31 (86%) reported having some kind of adverse experience, summarized in Table 2:

Logistical Problems

Perhaps because they cared for far fewer patients with ICDs (an average of 2.6 ICDs for rural programs compared to an average of 6.0 ICDs for urban [and higher census] programs in the last 24 months), rural programs were no more likely to report difficulties locating someone to deactivate an ICD compared to urban programs (29% vs. 42%, $p=0.35$).

Unwanted Shocks

Regarding unwanted shocks before and during the active dying phase, most were distressing to both patient and family. Qualitative data revealed that shocks occurring after death could cause distress for family members and hospice staff:

“The bath aide was with the wife during the death of the husband. After he stopped breathing his body continued to be shocked and his arms and legs jumped. She (the aide) wrapped the body tightly like a cocoon to prevent the flailing. The aide said it was a horrible event and the wife was distressed.”

Distress over decision to deactivate the ICD

Regarding the decision to deactivate an ICD, hospices were more likely to report family distress than patient distress (67% reported family distress vs. 47% reported patient distress, $t=-2.9$, $p=.006$). It may be that some hospices are opting to use magnets once the active dying phase begins rather than deactivating the devices beforehand as described by this story:

“Patient and spouse severely worried that turning off ICD would cause patient to die more quickly. Once decision was made, a smaller level of anxiety waiting for manufacturer to come over the next day to turn off. It is not uncommon for us to tape a magnet over (the) device to prevent the possibility of unnecessary shocks during actively dying phase”

Forty seven percent of programs reported difficulties around the decision to deactivate, as illustrated by this response from an urban hospice program:

“Family having difficulty with decision to deactivate ICD and waited too long. Unable to locate personnel to deactivate in patient home ‘after’ business hours had to transfer patient via ambulance to (emergency room) during dying process to have ICD deactivated. Patient died in (emergency room). Family and staff very upset.”

ICD Screening and Policies

Comparing programs with and without policies, programs without ICD policies were more somewhat likely to have had adverse events (65% vs. 46.7%) however this difference did not reach statistical significance ($p=.23$). The statistic that 38% of programs have no policy or screening perhaps understates the issue because they include the 3 programs with the largest censuses. One of these 3 programs added a note to their survey that they did not have a policy but that they had many patients with ICDs with no adverse events. They noted that because they were an integrated health maintenance organization with an electronic record, they could readily identify patients with ICDs and contact the responsible cardiologist to deal with the ICD.

One hospice program reported screening only patients admitted for cardiac diagnoses for ICDs. Given the increasing prevalence of ICDs this approach is likely to be insufficient as patients with ICDs may enter hospice with other terminal diagnoses, as illustrated by a story from a small rural hospice describing their lone experience with an ICD:

“Patient on hospice for lung cancer but had an ICD. The family called at time of death. When nurse arrived patient was “jerking” in the bed, the first shocks-which were stronger lifted him off the bed-very disturbing to family and nurse.”

Discussion

Across Oregon 86% of hospices reported caring for a patient with an ICD in the previous four years and 86% of those reported an adverse experience. When comparing Oregon data to a similar national survey about ICDs, 97% of national hospice programs reported admitting a patient with an active ICD the previous year with 58% reporting at least one adverse event from the ICD and 40% receiving multiple shocks during a single episode.¹⁸

In Oregon only 45% of programs routinely screen patients for ICDs and only 26% had a policy for managing ICDs. Although the proportion of Oregon programs with policies in place is low, it is higher than the national average of 10% reported by a recent US survey. Progressive advanced care planning in the state of Oregon may explain this finding.¹⁹

Should US hospice programs adopt policies for screening and managing ICDs? Nationally, patients enrolled in programs with policies are more likely to have their defibrillator deactivated than those on programs without policies.¹⁸ In this study, programs lacking policies were more likely to have experienced an adverse event, but the difference was not statistically significant. We argue that it would be better to develop a policy for managing ICDs *in advance of* an adverse event.

Is a policy necessary once a program has experience managing patients with ICDs? Rural programs were less likely to have policies, but they also had very few patients with ICDs and several programs without formal policies nevertheless described in the comments knowing how to use magnets and who to contact to get ICDs deactivated. In a recent national cross-sectional survey, Goldstein and colleagues did not find a causal relationship with hospices having a policy and device deactivation. Limitations of both our study and that of Goldstein and colleagues inadequately answer the question of causal relationship and beg further study. We argue that there is very little downside to having a policy in place and ICD use is continuing to increase. In particular, the policy can be used to educate new staff who may have never cared for a patient with an ICD or may not yet be familiar with local resources. .

Hospice policies and screening tools do not need to be extensive—simply adding a question on the admission intake form and checking the anterior chest wall just below the clavicle for the presence of a cardiac device. Once a patient is identified as having an ICD, the team needs to know what next steps to take including how to address deactivation with the patient, family, and attending cardiologist, how to get the device deactivated should that decision be made, and how to manage deactivating magnets in case of emergency. Several studies by Goldstein and others address the complexities of addressing ICD deactivation at the end of life.^{20,21,22,23}

Unwanted shock delivery was reported by 64% of programs, 42% of these were delivered during the active phase of dying. From the hospice programs' perspectives, these shocks were distressing in 96% of cases, either to the patient and family members, or to the family members alone (presumably in the case of an unresponsive patient). The term 'distress' may not do justice to how traumatizing these events can be for everyone involved. Not only must the patient, family, and hospice team deal with the patient's imminent death, but they must deal with the pain and panic induced by the shocks and loss of control. Several hospice programs reported they were not prepared for the shocks and did not have easy access to a magnet to deactivate the ICD.

Unfortunately, there is a significant knowledge gap among physicians about the medicolegal appropriateness of device deactivation.²⁴ A recent multidisciplinary collaboration by the Heart Rhythm Society conclude that deactivation of cardiac devices is both lawful and ethical based on precedents.¹⁶ For the patients and families discussing ICD deactivation with a hospice team member, programs reported 47% of both patient and families experienced distress related the deactivation decision. An additional 19% of family members reported being distressed and we suspect based on the qualitative comments that these were families who had to make the decision to deactivate after the patient was no longer able to participate in the decision. Assuming this is true it might help patients to understand that although talking about ICD deactivation can be distressing, by making their wishes known they can lift a burden from their loved ones should their family members be called to participate in deciding to deactivate the device.

This study has a number of limitations. First, many of the findings are not statistically significant in part because of the relatively small number of programs in Oregon, although we did achieve an excellent response rate to our survey. Second, we present only the perspective of the hospice programs as recalled by the program administrator or designee who may not have been directly involved in the patients' care. A survey of patient and family experiences with ICDs in hospice care would provide better measures of their distress. Despite these limitations, this study's mixed method approach adds useful information and counterpoints national survey data to provide a clearer picture of adverse experiences with implantable defibrillators in hospice care.

As patients near the end of their lives, receiving defibrillating shocks may no longer be consistent with their goals of care. Hospice programs have a clear responsibility to ensure that patients with ICDs do not suffer unnecessarily from unwanted shocks. Although this study was not designed to prove the effectiveness of screening for ICDs and policies for managing them, common sense suggests that programs that do not routinely screen for ICDs or take a passive rather than active approach to managing them are at risk for adverse outcomes. If nothing else, simply having a deactivating magnet readily available can prevent the most serious adverse outcome—unwanted shocks at the end of life. Based on the high frequencies of potentially preventable adverse outcomes documented by this study, we propose that hospices routinely screen patients for ICDs and adopt policies to proactively manage them, rather than in response to an adverse event. To assist programs in this process we offer a sample policy as Appendix A.

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Appendix A Sample

IMPLANTABLE CARDIOVERTER DEFIBRILLATOR PROTOCOL

Dying patients who have an implantable cardioverter defibrillator (ICD) may receive repeated defibrillator shocks during their last hours or minutes of life, which may cause a distressing or difficult death. Patients and families may experience a lingering and potentially unpleasant death by a defibrillator that discharges long after the device has outlived its life-prolonging potential.

When a patient is identified as having an activated ICD, the hospice team members will initiate this protocol.

1 Patient Identified As Having an Activated ICD:

- IDT team discusses documented patient's and/or family/loved one's wishes regarding quality of end of life, DNR order and the patient's request to stop automatic defibrillation at the active dying stage of life
- Hospice Medical Director collaborates with the Primary Physician and/or Cardiologist to review the case
- Hospice Medical Director schedules a home visit with the patient OR patient schedules an appt with the Primary Physician or Cardiologist to review the ICD

If patient chooses deactivation, go to Step 2. If patient chooses to keep ICD activated, go to Step 3.

2 Patient Chooses to Deactivate ICD:

- If Patient decides to deactivate the defibrillator, the hospice nurse contacts the device technician to schedule a time to deactivate the ICD
- Hospice MSW or RN includes patient/family deactivation request. POLST form is updated and physician signature is obtained
- RN updates the Hospice POC and call books

- When making a negative statement, place the object over the affirmative.

- How to place the magnet:

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- RN provides instruction handout and magnet to patient and/or family

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3 Patient Chooses to Keep ICD Active:

- RN updates the Hospice POC and call books
- The Physician will review the requirement to have a deactivating magnet in the home in the event of repeated shocks, and the immediate desire to deactivate the defibrillator
- The hospice nurse will bring a deactivating magnet to the patient's home
- RN will review how to use the magnet in the event of repeated shocks, and the patient's desire for immediate deactivation:
 - Instruct the family/ caregiver:
 - ICD function and palliative care treatment goals
 - When magnet is placed directly over a defibrillator it will suppress the defibrillator function. It does not turn off the pacemaker function of the device.
 - How to place the magnet:
 - If the magnet is applied

while the device is charging or delivering therapy, it will terminate the delivery of therapy after 1–2 seconds

- Continue to suppress therapy by taping the magnet over the device

- RN provides instruction handout and magnet to patient and/or family

- Attach form copy to nursing progress note in travel chart.

- RN provides for and documents follow-up care and teaching at subsequent visits as needed
- RN maintains communication with the IDT regarding status
- If the defibrillator remains active and the patient appears to be actively dying, the Hospice Medical Director will make a home visit to review the goals of care and re-visit option of permanent ICD deactivation

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Table 1

Characteristics of Responding Oregon Hospice Programs

	N = 42
Average Daily Census	73 patients
• Mean	88 patients
• Standard Deviation	40 patients
• Median	0 *
• Range	0–440 patients
Urban vs. Rural	29 (69%) rural
Not for profit vs. proprietary	34 (81%) not for profit
Percentage of patients with primary cardiac diagnoses:	4 (9.5%)
• <5% (i.e. much less than the Oregon hospice average)	16 (38.1%)
• 6–11% (i.e. less than the Oregon hospice average)	10 (23.8%)
• 12% (i.e. about the Oregon hospice average)	10 (23.8%)
• 13–20% (i.e. more than the Oregon hospice average)	0 (0%)
• >20% (i.e. much more than the Oregon hospice average)	2 (4.8%)
• No response	
How skillful is your program in caring for heart disease?	6 (14.3%)
• Less skillful for heart disease than for cancer	36 (85.7%)
• Equally skillful for heart disease and cancer	0.0%
• More skillful for heart disease than for cancer	

* One program, affiliated with a correctional institution, reported having an average census of 0.

Table 2

Adverse experiences with ICDs

For programs that had cared for a patient with an ICD (n = 36)	
Reported any adverse experience	31 (86%)
Reported difficulty locating someone to deactivate ICD	12 (33%)
Reported time delay before the ICD could be deactivated	15 (42%)
Reported caring for a patient who experienced unwanted shocks	23 (64%)
• Unwanted shocks before active dying phase	4 (11%)
• Unwanted shocks during active dying phase	10 (28%)
• Both	5 (14%)
Reported never having cared for a patient who experienced unwanted shocks	13 (36%)
For programs that had cared for a patient who received unwanted shocks (n = 23)	
Distress related to unwanted shocks	1 (4%)
• Patient only distressed by shocks	5 (22%)
• Family only distressed by shocks	16 (70%)
• Both distressed by shocks	1 (4%)
• Neither distressed by shocks	
For programs that had cared for a patient with an ICD (n=36)	
Distress related to ICD deactivation	29 (81%)
• % of programs deactivating an ICD in a patient	17 (47%)
• Hospice reported difficulty around decision	
For programs that reported deactivating an ICD (n=29)	
• Patient only distressed by decision	0 (0%)
• Family only distressed by decision	7 (24%)
• Both distressed by decision	12 (41%)
• Neither distressed by decision	10 (34%)

Table 3

Policies or screening processes

	%
A policy addressing how ICDs should be managed	11 (26.2%)
A policy defining necessary steps that must be followed before electively (i.e. not in an emergency) deactivating an ICD	11 (26.2%)
A requirement that patients with ICDs be offered a deactivating magnet to keep in the home	8 (19%)
A requirement that patients with ICDs keep a deactivating magnet in the home	5 (11.9%)
Any of the above policies or requirements	16 (38%)
A requirement that all new patients are screened for ICDs	19 (45.2%)
No policy or screening	16 (38%)