# Barriers to Conversations about Deactivation of Implantable Defibrillators in Seriously ill Patients: Results of a Nation Wide Survey Comparing Cardiology Specialists to Primary Care Physicians

**Nathan E. Goldstein, MD**[*,†], **Elizabeth Bradley, PhD**[‡], **Jessica Zeidman, BA**[*], **Davendra Mehta, MD, PhD**[§], and **R. Sean Morrison, MD**[*,†]

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

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

[‡]Robert Wood Johnson Clinical Scholars Program and Department of Epidemiology and Public Health, Yale University School of Medicine, New Haven, CT

[§]Section of Electrophysiology, Division of Cardiology, Department of Medicine, Mount Sinai School of Medicine, New York, NY

Implantable Cardioverter-Defibrillators (ICDs) reduce sudden cardiac death. However, about 25% of patients with ICDs are shocked in the last month of life(1), and these shocks may cause frightening and painful deaths. Little is known about how physicians' attitudes influence their decisions to discuss ICD deactivation with patients.

We created a simple random sample of the American Medical Association Masterfile by choosing 100 physicians from each of four strata: electrophysiologists, cardiologists, geriatricians, and internists. Eligible clinicians had to be in active practice and had to have cared for at least one patient with an ICD. We mailed letters to all physicians introducing the study, and then followed up by telephone to administer the survey. Physicians who could not be contacted telephonically were mailed surveys, and a series of incentives were used to encourage participation. All surveys were anonymous. This project was exempt from review by the Mount Sinai School of Medicine IRB.

We based the survey on our previous qualitative work.(2,3) The instrument included Likert scales (1 (strongly disagree) to 5 (strongly agree)) to determine physicians' attitudes relating to ICD conversations (Table 1). Data were analyzed as both continuous and dichotomous variables. As the results of these analyses were similar, the Likert scales are reported as strongly agree or agree versus all others. For between group comparisons, the chi-square test was used; Fisher's Exact test was used for smaller cell sizes. P-values reflect comparisons across the four groups. There was no difference in response patterns between phone and written surveys. ANOVA was used to evaluate the differences in age of respondents across the four groups. Significance levels for individual tests were not adjusted as the survey was based on qualitative data and the sample size was small thus making it unlikely that any

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.

observed association would be due to chance alone.(4) All calculations were performed using SAS v9.0 (Cary, NC).

Of the 400 physicians selected for the survey, 11 were deemed ineligible (7 were retired and 4 had never cared for a patient with an ICD) and 52 could not be located. Of the remaining 337 eligible physicians, 147 completed surveys, yielding a response rate among physicians who could be located of 44% (147/337). Electrophysiologists had a higher response rate (58%) compared with cardiologists (36%), internists (37%) and geriatricians (41%) (p=.013). Geriatricians tended to be older than cardiologists, electrophysiologists, or internists (mean age 54.1 years vs. 48.3, 49.0, and 48.1 respectively, p-value<0.001). The likelihood of being male was higher among electrophysiologists (92%) and cardiologists (93%) than among geriatricians (62%) and internists (66%) (p-value<0.001).

Clinicians' views about care for seriously ill patients with ICDs varied across specialty. Electrophysiologists were less likely than cardiologists, internists, or geriatricians to agree/strongly agree that they could accurately predict the possibility of a patient being shocked by the ICD near the end of life (12% versus 41%, 46%, and 30%, respectively) (p=.005). With respect to patient understanding, 94% of electrophysiologists and 93% of cardiologists who responded strongly agreed/agreed with the statement that their patients understood why they had an ICD, whereas only 74% of internists and 77% of geriatricians agreed with this statement (p=0.03). Sixty three percent of electrophysiologists, 45% of cardiologists, 33% of internists, and 55% of geriatricians believed patients knew they could deactivate their ICD (p=.11).

One potential barrier to ICD deactivation discussions may relate to physician's beliefs that they can predict which patients will receive a shock. In reality it can be difficult to predict the terminal cardiac rhythm. Physicians who believe they can predict who will be shocked may fail to discuss deactivation with patients for whom they mistakenly believe ICD firing is unlikely.

Clinicians may be unaware of patients' understanding about their devices. Most clinicians in every group believed their patients understood the indication for their device, which might limit their belief that more discussion is needed. Data from patient focus groups, however, reveal that they do not know the indication for their device and that their understanding of its purpose varies widely and is often inaccurate.(2)

A final barrier may be that many physicians (in our study 1/3 of internists and 2/3 of electrophysiologists) believed that patients already knew they could deactivate the shocking function of their ICD. Prior data suggest that patients with ICDs often do not know that this is possible.(2) Clinicians who believe that patients know the options for device management at the end of life may be less likely to have deactivation conversations.

This study has limitations. The rate of surveys completed was less than 50%. Nevertheless, our enrollment rate is consistent with other clinician surveys reporting on patients with advanced illness.(5) Electrophysiologists were more likely to respond as compared to others: perhaps because they take more "ownership" of the issue of deactivation because it involves a device they implant.

This study identifies clinician perceptions that may reflect barriers to communication about deactivation of ICDs in patients with advanced illness. The focus of this work is on barriers to conversations as we believe that these conversations should occur as part of conversations about advance care planning; whether the device is deactivated is the decision of the patient and family. Because patients with ICDs are cared for by physicians of a variety of specialties with differing views, future interventions to improve conversations about device

deactivation should be targeted at both specialists and generalists with the appropriate timing of these conversations determined by subsequent empirical studies.

## Acknowledgments

## References

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**Table 1**

**Results of 5-point Likert scales to Determine Physicians' Attitudes Relating to Care of Patients with ICDs**

Clinicians were asked to rate the following statements on a scale of 1-5 where 1 was "Strongly Disagree", 3 was "Neither Agree not Disagree" and 5 was "Strongly Agree." For purposes of clarity in reporting these data, the investigators report the Likert scales as strongly agree or agree (noted in table as "agree") versus all others (noted in table as "neutral/disagree). Instruction included that if there was no mention about an ICD in a particular statement, then the statement was a global question relating to their overall practice. P-values reflect comparisons across the four groups of clinicians. All results were obtained using the Chi-Square test, unless cell sizes were <5.

| | | Cardiologists n (%) | Electrophysiologists n (%) | Geriatricians n (%) | Internists n (%) | P |
|---|---|---|---|---|---|---|
| I feel confident in my clinical skills in dealing with patients at the end of life. | Agree | 25 (86) | 41 (84) | 35 (97) | 25 (83) | .17[*] |
| | Neutral/Disagree | 4 (14) | 8 (16) | 1 (3) | 5 (17) | |
| I feel comfortable with my skills in communicating with patients about treatment options near the end of life. | Agree | 26 (90) | 43 (88) | 35 (100) | 27 (90) | .14[*] |
| | Neutral/Disagree | 3 (10) | 6 (12) | 0 (0) | 3 (10) | |
| A bad experience with a past conversation about ICD deactivation makes me reluctant to have future conversations about deactivation with patients. | Agree | 2 (8) | 0 (0) | 1 (7) | 0 (0) | .18[*] |
| | Neutral/Disagree | 24 (92) | 45 (100) | 13 (93) | 10 (100) | |
| I feel confident that I can reasonably estimate a patient's life-expectancy. | Agree | 8 (28) | 15 (31) | 12 (35) | 11 (42) | .68 |
| | Neutral/Disagree | 21 (72) | 33 (69) | 22 (65) | 15 (58) | |
| I am confident that I can accurately predict the | | | | | | |

| | Cardiologists n (%) | Electrophysiologists n (%) | Geriatricians n (%) | Internists n (%) | P |
|---|---|---|---|---|---|
| possibility of a patient being shocked by the ICD near the end of life. | | | | | |
| Agree | 12 (41) | 6 (12) | 9 (30) | 11 (46) | .005 |
| Neutral/Disagree | 17 (59) | 43 (88) | 21 (70) | 13 (54) | |
| I believe that my role is to make the decision for a patient in terms of the best medical treatments. | | | | | |
| Agree | 11 (38) | 16 (33) | 18 (50) | 16 (53) | .25 |
| Neutral/Disagree | 18 (62) | 32 (67) | 18 (50) | 14 (47) | |
| I believe that my role is to solely inform patients of their treatment options and then let them make the decision on their own. | | | | | |
| Agree | 16 (55) | 20 (41) | 18 (51) | 18 (60) | .37 |
| Neutral/Disagree | 13 (45) | 29 (59) | 17 (49) | 12 (40) | |
| I believe that my role is to work with the patient to share decision making about the best treatments. | | | | | |
| Agree | 27 (93) | 44 (92) | 32 (89) | 28 (93) | .93[*] |
| Neutral/Disagree | 2 (7) | 4 (8) | 4 (11) | 2 (7) | |
| I think that my patients understand why they have an ICD. | | | | | |
| Agree | 27 (93) | 46 (94) | 27 (77) | 20 (74) | 0.03[*] |
| Neutral/Disagree | 2 (7) | 3 (6) | 8 (23) | 7 (26) | |
| I think that my patients know that if they so choose, they can deactivate the portions of their ICD that may cause discomfort to them (i.e. cardioversion or defibrillation functions). | | | | | |

| | | Cardiologists n (%) | Electrophysiologists n (%) | Geriatricians n (%) | Internists n (%) | P |
|---|---|---|---|---|---|---|
| I feel that I have adequate time to be able to discuss treatments with patients. | Agree | 13 (45) | 31 (63) | 17 (55) | 7 (33) | .11 |
| | Neutral/Disagree | 16 (55) | 18 (37) | 14 (45) | 14 (67) | |
| Uncertainty about a patient's prognosis prevents me from engaging in conversations about ICD deactivation. | Agree | 23 (77) | 33 (67) | 19 (54) | 14 (48) | .09 |
| | Neutral/Disagree | 7 (23) | 16 (33) | 16 (46) | 15 (52) | |
| I only feel comfortable having conversations about ICD deactivation with patients with whom I have a well-established relationship. | Agree | 10 (33) | 12 (24) | 4 (13) | 6 (24) | .34* |
| | Neutral/Disagree | 20 (67) | 37 (76) | 26 (87) | 19 (76) | |
| Positive experiences with past ICD deactivation discussions have encouraged me to have these conversations with my patients. | Agree | 11 (38) | 22 (46) | 14 (44) | 6 (29) | .57 |
| | Neutral/Disagree | 18 (62) | 26 (54) | 18 (56) | 15 (71) | |
| If a patient is hospitalized frequently, I am/would be more inclined to discuss deactivation with him/her. | Agree | 13 (54) | 29 (62) | 10 (63) | 6 (55) | .90 |
| | Neutral/Disagree | 11 (46) | 18 (38) | 6 (38) | 5 (45) | |
| | Agree | 11 (37) | 20 (42) | 16 (52) | 9 (39) | .67 |

| | | Cardiologists n (%) | Electrophysiologists n (%) | Geriatricians n (%) | Internists n (%) | P |
|---|---|---|---|---|---|---|
| | Neutral/Disagree | 19 (63) | 28 (58) | 15 (48) | 14 (61) | |
| If a patient has worsening organ function I am/would be more inclined to discuss deactivation with him/her. | Agree | 25 (83) | 39 (81) | 26 (84) | 16 (70) | .56 |
| | Neutral/Disagree | 5 (17) | 9 (19) | 5 (16) | 7 (30) | |

*For these Fisher's Exact test was used, and those comparisons are noted below by next to the p-value.