

**TABLE 1. SELECTED RESEARCH STUDIES PERTAINING TO ICD DEACTIVATION IN END-OF-LIFE CARE (N = 14)**<sup>11-14, 17, 46-54</sup>

Study	Sample	Study Design, Purpose, and Methods or Intervention	Measured Outcomes or Findings	Limitations and Comments
Goldstein NE, et al. <i>Ann Intern Med</i> 2004;141(11):835-8.	Next of kin (N = 100) of patients who'd received ICDs at Yale–New Haven Hospital and had died of any cause between 1997 and 2002	Retrospective cohort study aimed at describing frequency, timing, and correlates of ICD deactivation discussions. Telephone interview using a form adapted from the After-Death Bereaved Family Interview tool.	Incidence of deactivation discussions: n = 27 (27%) Timing of deactivation discussions: <ul style="list-style-type: none"> <li>• within last few days of patient's life, 74%</li> <li>• within last few hours of patient's life, 22%</li> <li>• within last few minutes of patient's life, 4%</li> </ul> Patients with DNR orders having deactivation discussions: n = 21 (45%), 95% CI [for proportion], 30-60	Interviews were conducted a median of 2.3 years after patient death; study relied on the recall of next of kin.
Goldstein NE, et al. <i>J Gen Intern Med</i> 2008;23 Suppl 1:7-12.	Community-dwelling, ambulatory patients with ICDs (N = 15)	Qualitative study of focus groups, moderated by a physician and social worker. Using open-ended questions, researchers sought to reveal participants' understanding of ICD function and options and to identify barriers to deactivation. (Two hypothetical scenarios were also presented.)	Themes that emerged: <ul style="list-style-type: none"> <li>• Participants didn't understand role their ICDs played in their health.</li> <li>• Participants wouldn't engage in discussions about deactivation either during focus groups or with their own clinicians; at least two felt their physicians should make deactivation decisions.</li> <li>• Participants appeared to have developed a complex psychological relationship with their ICDs.</li> </ul>	No participants had major comorbidities; all were patients at the same facility. A selection bias may exist.
Goldstein NE, et al. <i>J Gen Intern Med</i> 2008;23 Suppl 1:2-6.	Electrophysiologists, cardiologists, and generalists (internists and geriatricians) from New York, New Jersey, and Connecticut (N = 12)	Qualitative study involving one-on-one interviews, using open-ended questions to elicit participants' past experiences with discussing ICD deactivation	Themes that emerged: <ul style="list-style-type: none"> <li>• Almost all participants agreed conversations about ICD deactivation should be included in advance planning discussions, but acknowledged this rarely happened.</li> <li>• Participants "postulated that there was something intrinsic to the nature and function of [ICDs] that made it inherently difficult to think of them in the same context" as other end-of-life management options.</li> <li>• Physicians lacked "the sense of rapport with patients to be able to discuss ICD deactivation."</li> </ul>	Study limited to greater New York area; cultural bias may exist.
Goldstein NE, et al. <i>J Am Coll Cardiol</i> 2009;54(4):371-4.	Physicians in active practice who had cared for at least 1 patient with an ICD (N = 147)	Random survey of electrophysiologists, cardiologists, geriatricians, and internists. Tool used statements with Likert-scale response options to determine physicians' attitudes on caring for seriously ill patients with ICDs. Surveys were conducted by telephone (or by mail if unreachable by telephone).	Physicians' views varied across specialties. Electrophysiologists, cardiologists, internists, and geriatricians <ul style="list-style-type: none"> <li>• believed patients knew why they had an ICD—94%, 93%, 74%, and 77%, respectively (<math>P = 0.03</math>).</li> <li>• believed patients knew they could deactivate portions of ICD therapy that might cause discomfort—63%, 45%, 33%, and 55%, respectively (<math>P = 0.11</math>).</li> <li>• felt comfortable with their skills in communicating treatment options near end of life—88%, 90%, 90%, and 100%, respectively (<math>P = 0.14</math>).</li> </ul>	Response rate was less than 50%, with greater response from electrophysiologists than other specialties. Self-report bias may exist.
Goldstein NE, et al. <i>Ann Intern Med</i> 2010;152(5):296-9.	Hospices (N = 416)	National survey of randomly selected hospices, weighted geographically. Goals were to determine frequency of admission of ICD patients, frequency of shocks they receive, and processes used to care for ICD patients.	Hospices having a policy addressing deactivation, 10% Hospices with such a policy were more likely to have a higher mean percentage of patients with ICDs deactivated than hospices without a policy (73% vs. 38%, $P < 0.001$ ).	Study relied on knowledge of hospice administrators. Self-report bias may exist.

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Hauptman PJ, et al. <i>Am J Med</i> 2008; 121(2):127-35.	Eligible physician respondents (N = 734)	Survey using a stratified random sampling of physicians (cardiologists, geriatricians, and internists/family practitioners) to better understand physician decision making in end-stage heart failure	As many as 75.4% (internists/family practitioners) reported never having discussed ICD deactivation with a patient or family member. Frequency of conversations about deactivation was associated with <ul style="list-style-type: none"> <li>• cardiology specialty (OR 5.07, 95% CI, 4.82-5.34).</li> <li>• formal training in palliative care (OR 1.43, 95% CI, 1.38-1.5).</li> <li>• use of guidelines in clinical setting (OR 3.22, 95% CI, 2.9-3.58).</li> <li>• group practice setting (OR 1.84, 95% CI, 1.77-1.92).</li> </ul>	Accuracy of physician self-reports not well established. Impact of physician attitudes on care selection unknown.
Kelley AS, et al. <i>Am J Hosp Palliat Care</i> 2008;25(6):440-6.	Physicians, stratified by specialty: general internists, cardiologists, geriatricians, and electrophysiologists. This study focused on the responses of participants (N = 177) who wrote independent comments.	Random survey, qualitative analysis. Mailed questionnaires included 5 vignettes depicting patients with ICDs and newly diagnosed terminal illnesses, 17 items with Likert-scale response options, and separate section for independent comments.	Among respondents, <ul style="list-style-type: none"> <li>• 12% would postpone deactivation discussion until a future time.</li> <li>• 21% would suggest additional treatments or therapies before discussing deactivation.</li> <li>• 7% thought the patient or a family member should initiate such discussion.</li> <li>• 10% thought another physician should initiate such discussion.</li> <li>• 13% accepted primary responsibility for initiating such discussion.</li> <li>• 9% expressed a lack of awareness of ICD function and deactivation options.</li> <li>• 6% had never thought about ICD deactivation.</li> </ul>	Potential selection bias due to low return rate. Generalizability of findings limited. Use of vignettes is a limitation.
Kelley AS, et al. <i>Am Heart J</i> 2009; 157(4):702-8.e1.	Physicians, stratified by specialty: general internists, cardiologists, geriatricians, and electrophysiologists. This study focused on the responses of participants (N = 558) to close-ended survey questions.	Random survey, quantitative analysis. Mailed questionnaires, included 5 vignettes depicting patients with ICDs and newly diagnosed terminal illnesses, 17 items with Likert-scale response options, and separate section for independent comments.	Among all respondents, depending on vignette, <ul style="list-style-type: none"> <li>• 80%–94% would discuss advance directives and DNR.</li> <li>• 56%–83% would discuss ICD deactivation.</li> </ul> History of prior deactivation discussions predicted willingness to discuss deactivation in 4 of 5 vignettes. <p>58% of all respondents would prefer expert guidance in discussing deactivation.</p> Physicians' views varied across specialties. General internists, geriatricians, cardiologists, and electrophysiologists <ul style="list-style-type: none"> <li>• agreed that expert guidance regarding ongoing management of patients with ICDs would be helpful—86%, 76%, 52%, and 34%, respectively (<math>P &lt; 0.001</math>).</li> <li>• believed that informed consent process for implantation should include information about deactivation options—95%, 95%, 79%, and 56%, respectively (<math>P &lt; 0.001</math>).</li> <li>• felt that ICD shocks at end of life were distressing to patient, family, or both—65%, 73%, 70%, and 85%, respectively (<math>P = 0.001</math>).</li> </ul>	Potential selection/response bias due to low return rate. Generalizability of findings limited. Use of vignettes is a limitation.
Kobza R, Erne P. <i>Pacing Clin Electrophysiol</i> 2007;30(7):845-9.	Patients with ICDs implanted at Kantonsspital Luzern, Switzerland, between January 1, 1994, and January 31, 2007, and who died between January 1, 1998, and January 31, 2007 (N = 36)	Retrospective review of records to determine whether ICD deactivation had been discussed and, if so, what the patients had decided.	Eight patients with ICDs (22.2%) had been diagnosed with malignant tumors. Records indicated that with six of the eight, withdrawal of ICD therapy had been discussed "extensively." None of the patients who had discussed this option elected to do so.	No standard protocols existed for holding deactivation discussions or for decision making among the patients and physicians. Study limited to a facility in Switzerland; cultural bias may exist.

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Lewis WR, et al. <i>Am J Med</i> 2006;119(10):892-6.	Deceased patients with ICDs (N = 63)	Retrospective review. An interdisciplinary strategy to identify terminally ill patients and initiate withdrawal of ICD shock therapy had been implemented as part of comfort care. After implementation, charts of 63 of 90 patients who died between January 1994 and February 2004 were reviewed.	Two groups emerged: patients with terminal illnesses identified during routine follow-up (group 1, n = 20) and patients without identifiable terminal illnesses at routine follow-up (group 2, n = 43). Data suggest that "an identifiable chronic terminal illness can be anticipated in 32% of patients."  Device deactivation was chosen by 100% of patients in group 1 compared with 0% of those in group 2.	One health care system studied. No randomization of patients. Deactivation discussions not standardized.
Marinskis G, van Erven L. <i>Europace</i> 2010;12(8):1176-7.	Physicians from 47 centers of the European Heart Rhythm Association's Research Network; 82% of respondents were electrophysiologists, 12% were general cardiologists.	Electronic Web-based survey presenting clinical scenarios	4% of respondents indicated that device deactivation was routinely discussed at time of implantation. 85% indicated that deactivation discussions occurred only in specific cases during follow-up. 75% considered expert guidelines for ICD deactivation helpful. 62% indicated that they'd discuss deactivation at patient's end of life. 83% would deactivate ICD in terminally ill patients who were receiving multiple shocks.	Study limited to specialists at centers involved in cardiology research. Results may not reflect all specialties or facilities. Potential bias in self-report.
Mueller PS, et al. <i>Pacing Clin Electrophysiol</i> 2008;31(5):560-8.	Heart Rhythm Society members (physicians, nurses, and others) and field representatives of the cardiac rhythm management divisions of two ICD manufacturers (N = 787)	Anonymous, Web-based survey to describe practices and attitudes about pacemaker and ICD deactivation in terminally ill patients	Respondents reported that, in their experience, 59.3% of ICD deactivations were performed by industry representatives. Among all respondents, 56.7% said they'd be comfortable deactivating a device following a request by a terminally ill patient. 24.7% felt a physician should be present during device deactivation. 37% felt terminally ill patients requesting device deactivation should first undergo psychiatric evaluation. 28.3% felt they should first have an ethics consultation.	Potential selection bias due to low return rate (18%). Generalizability of findings limited. Free text comments not included in this analysis.
Sherazi S, et al. <i>Mayo Clin Proc</i> 2008;83(10):1139-41.	Physicians in the Department of Medicine of the Unity Health System in Rochester, NY (N = 87)	Cross-sectional survey was mailed to physicians to gather information about their knowledge and preferences regarding medical, ethical, and legal issues related to caring for terminally ill patients with ICDs.	46% of respondents either thought ICD deactivation in terminally ill patients was illegal or were unsure of its legality. 22% were uncomfortable deactivating an ICD in a terminally ill patient. 59% believed an ICD-delivered shock would be painful for the patient.	Convenience sample, all participants were from one health care system. Findings may represent a bias.
Stewart GC, et al. <i>J Card Fail</i> 2010;16(2):106-13.	Patients with ejection fraction < 35% and symptomatic heart failure, without history of ventricular tachycardia, ventricular fibrillation, or syncope (N = 105); some had ICDs (n = 67) and some didn't (n = 38)	Written survey including hypothetical scenarios of terminal illness. At the beginning, participants read that an ICD is designed to prevent only sudden cardiac death.	70% of ICD recipients indicated their physician was the primary source of information regarding their device.  Comparing ICD recipients to patients without ICDs: ICD recipients were more confident of lifesaving ability of device (67% vs. 19%, $P < 0.001$ ); ICD recipients had better understanding of deactivation option (73% vs. 42%, $P = 0.016$ )  Among ICD recipients given hypothetical scenarios of terminal illness: 39% indicated they would never have device deactivated; 55% indicated they would keep it on even if experiencing daily shocks; 70% indicated they would keep it on even if dying of cancer or would die within 1 month from a noncardiac cause. None would elect deactivation even if experiencing constant dyspnea.	Study participants were from two Boston heart failure referral centers. Selection bias may exist. Survey wasn't independently validated. Results are in the context of hypothetical scenarios. ICD recipient responses weren't stratified for history of prior shocks; a response bias may exist.

CI = confidence interval; DNR = do not resuscitate; ICD = implantable cardioverter-defibrillator; OR = odds ratio.