Patient Preferences for Deactivation of Implantable Cardioverter-Defibrillators

While implantable cardioverter-defibrillators (ICDs) prolong life, painful shocks can occur at the end of life, and physicians rarely discuss the option of device deactivation.1,2 To prevent shocks at the end of life that do not meaningfully prolong survival, a recent Heart Rhythm Society consensus statement recommended proactive communication with patients regarding deactivation.3 However, most surveys have found that the majority of ICD patients would not consider deactivation even in deleterious future health states including terminal cancer,4 constant dyspnea,5 or frequent shocks.5,6

We examined preferences for ICD deactivation in the context of health outcomes such as functional and cognitive disabilities shown to matter most to patients.7 Our survey provided an informational description of the potential benefits and burdens of the shocking function of ICDs and subsequently presented scenarios describing broad health outcomes common in patients approaching the end of life.

See Invited Commentary at end of letter

Methods. We recruited ICD patients 50 years and older who were followed in a single academic electrophysiology practice (Yale University). Eligible participants were English speaking and had received a new ICD implant or generator change between January 1, 2006, and December 31, 2009. We excluded patients who were cognitively impaired, had an initial device within the past year, or had a cardiac resynchronization therapy-capable device. Eligible participants were contacted by telephone by 1 investigator (J.A.D.), and those consenting were administered a 20-minute telephone survey. The study was approved by the Yale Human Investigation Committee.

The survey (eAppendix; http://www.jamainternalmed.com) included 2 open-ended questions: “What do you feel are the potential benefits of your ICD?” and “What do you feel are the potential harms of your ICD?” Responses were transcribed and later categorized by 3 investigators (J.A.D., T.R.F., and R.L.), with discrepancies resolved through consensus. Participants were then read a standardized script providing the best current evidence regarding benefits and burdens of ICDs. Subsequently, participants were asked whether they would want their ICD deactivated in 5 scenarios representing key domains of health that strongly influence treatment preferences.7 The scenarios were as follows: (1) permanently unable to get out of bed, (2) permanent memory problems, (3) burden to family members, (4) prolonged mechanical ventilation (>1 month), and (5) advanced incurable disease. Participants responded using a scale of 1 (“definitely no”) to 5 (“definitely yes”); they were classified as wanting deactivation if they responded “possibly yes” or “definitely yes” to at least 1 scenario.

Results. Of 136 eligible patients contacted, 95 (70%) agreed to participate. The mean (SD) age was 71.4 (10.6) years, 28% were female, and 19% were nonwhite. The mean (SD) duration of ICD placement was 4.0 (2.4) years prior, and 29% of participants had received a prior ICD shock.

Thirty-one participants reported “unknown” or “no” benefits of their ICD. Other responses were categorized as restarting the heart (n=31), living longer (n=27), improving quality of life (n=7), other (n=4) [3 patients thought the ICD prevented atrial fibrillation or stroke and 1 thought that it improved heart function]]. Sixty participants could not name a potential harm. The remaining categories were receiving a shock (n=14), device mal-

Categories of responses for potential harms of ICD, with representative quotes

- **Getting shocked (n=14)**
  - “I don’t like living with the worry that this machine is going to go off at any second.”
  - “I got scared when I got a shock. I’ve been scared since then.”
  - “I hope that it never goes off. If it does they say it’s like getting hit by a Mack truck.”
- **Device malfunction (n=8)**
  - “I got a defective one and it had to be changed.”
  - “Something happened with the old one—it went off 8 times in succession. That scared me; they had to replace the whole thing.”
  - “The recall on the wires. They adjusted the pacemaker aspect and now it’s OK.”
- **Nuisance/discomfort (n=5)**
  - “It’s a nuisance when I’m flying.”
  - “Sometimes it’s uncomfortable.”
  - “Complication (infection/bleeding) (n=2)
  - “I had an infection and the device had to be removed.”
  - “I had some bleeding after implantation.”
- **End of life (n=2)**
  - “That were my life to be nearing its end due to non-heart problems, that it would cause me a lot of pain when it was time to go.”
  - “None—unless I get in a horrible accident and it keeps calling me back.”
- **Other (n=4)**
  - “I feel it there and sometimes I’m afraid when I touch it.”
  - “It bothers me when I sleep on the left-hand side. I’m a little afraid that the leads might come out.”
  - “The possibility of injuring the device if I fall down.”

Categories of responses for potential benefits of ICD, with representative quotes

- **Restarting heart (n=31)**
  - “In case of an event where my heart stops or goes into fibrillation—it will need to zap me.”
  - “It will shock me if I’m having an episode. I like the security of knowing there’s something there because I’m by myself.”
  - “It’s peace of mind—knowing that if I go into a cardiac arrest there’s something there. I don’t have to wait for other people to get there.”
- **Living longer (n=27)**
  - “It gives me another lease on life.”
  - “I’ll probably save my life one of these days.”
  - “They said I wouldn’t make it to the hospital if I didn’t have it.”
- **Quality of life (n=7)**
  - “It’s helped me tremendously. I don’t have the dizziness, the passing out. I have more energy.”
  - “It helps with my congestive heart failure; it helps with the fluid in my lungs.”
- **Other benefits (n=4)**
  - “I’ve got a-fib and the way I see it, if it gets worse this is going to help straighten it out.”
  - “God forbid if I would have a stroke, it would prevent it.”

Categorization of responses for potential harms of ICD, with representative quotes

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  - “I don’t like living with the worry that this machine is going to go off at any second.”
  - “I got scared when I got a shock. I’ve been scared since then.”
  - “I hope that it never goes off. If it does they say it’s like getting hit by a Mack truck.”
- **Device malfunction (n=8)**
  - “I got a defective one and it had to be changed.”
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  - “The recall on the wires. They adjusted the pacemaker aspect and now it’s OK.”
- **Nuisance/discomfort (n=5)**
  - “It’s a nuisance when I’m flying.”
  - “Sometimes it’s uncomfortable.”
  - “Complication (infection/bleeding) (n=2)
  - “I had an infection and the device had to be removed.”
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- **End of life (n=2)**
  - “That were my life to be nearing its end due to non-heart problems, that it would cause me a lot of pain when it was time to go.”
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- **Other (n=4)**
  - “I feel it there and sometimes I’m afraid when I touch it.”
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Figure. Qualitative and quantitative results. a-fib Indicates atrial fibrillation; ICD, implantable cardioverter-defibrillator.
function (n=8), nuisance (n=5), complication (infection or bleeding) (n=2), inappropriate end-of-life shocks (n=2), and other (n=4 [1 was related to a phantom shock and 3 were related to unrealistic fears regarding harming the device—by lying down, touching the device, or falling]) (Figure).

Sixty-seven participants (71%) wanted ICD deactivation in 1 or more scenarios. Responses to individual scenarios ranged from 61% wanting deactivation in the setting of advanced incurable disease to 24% wanting deactivation if permanently unable to get out of bed (eFigure). Participant characteristics associated with wanting deactivation included race and disability but not age (Table).

Comment. In contrast to prior findings, in our study, following an informational script the majority (71%) of participants wanted ICD deactivation in at least 1 scenario describing health outcomes that are common in patients approaching the end of life.

There are several potential explanations for why our findings differ from prior investigations suggesting that the majority of patients would not want deactivation even in scenarios reflecting advanced illness. One may be the age of our study sample, which consisted exclusively of older individuals (age ≥50 years). Another may be the study protocol, which involved reading each participant an informational script explaining the purpose of their ICD. Our qualitative finding that a sizeable number of participants did not have a good understanding of the benefits or potential burdens of their ICD underscores this possibility and highlights the importance of physician communication of information. Finally, we included a broad range of scenarios reflecting outcomes of advanced functional, cognitive, and medical illness, which further highlight the importance of communication in the framework of goal setting around desired health states, since tolerance for shocks and discomfort will be based on the ultimate perceived outcome. We believe that our findings emphasize the importance of incorporating multiple patient-centered outcomes into advance care planning for ICD patients.

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Online-Only Material: The eAppendix and eFigure are available at http://www.jamainternalmed.com.


As the authors note, this finding is in contrast with prior surveys in which most patients say that they would not want to deactivate their ICD even if they were living with an advanced illness.4 Why were patients in this study more likely to say that they would deactivate their ICD in certain scenarios? The authors hypothesize that it may have been because their protocol involved an informational script. We agree and propose that the survey went further to create a process that helped patients consider and clarify their preferences. In effect, the survey may have become a successful decision-making intervention.

Many patients with ICDs are unaware that it is possible to deactivate an ICD. We know that knowledge influences decisions. Thus, by introducing the topic of deactivation at the beginning of the survey, by explaining patient knowledge surrounding the pros and cons of ICDs, by clarifying their knowledge about deactivation, and then by reading and asking for a response to a series of 5 specific clinical scenarios about deactivation, they may have created a situation where postsurvey respondents were in a new place philosophically regarding ICD deactivation.

The dual-process theory of decision making argues that people process decisions either “intuitively,” quickly drawing on past experiences and emotion, or “reasonably,” using a more thoughtful, analytic approach. This theory is foundational in the growing field of behavioral economics and is the topic of a recent book called Thinking Fast and Slow by Nobel laureate Dan Kahneman.5 According to a Cochrane review of 86 randomized trials of decision aids, when people go through a more reasoned process, their decisions are more likely to be better informed, based on more accurate expectations, and more concordant with their stated values.6 Patients faced with decisions regarding ICD deactivation may quickly and intuitively seize on the prevention of sudden death. However, those same patients may also prefer to die peacefully in their sleep without prolonged suffering in the face of incurable disease. Thus, for patients with ICDs, a more reasoned approach is required to allow the patient to weigh the consequences of ongoing device function vs deactivation.

Any complex decision involving life and death is nuanced, and there are likely to be multiple explanations for the unique findings found in the survey by Dodson et al.4 First, these patients were older than those surveyed in other studies, had their ICD for an average of 4 years, and 71% had not experienced a shock. The conclusion that patients were more willing to deactivate their device and less likely to be able to explain its risks and benefits may in part reflect that for many of these participants the ICD has been of relatively minor significance in their recent lives (positively or negatively). Second, the authors found that respondents were increasingly likely to deactivate their ICD through the 5 scenarios. Perhaps this was less a function of the specific content of the individual scenarios and more a function of having just spent 4 prior scenarios imagining death. It would have been interesting to see if presenting the scenarios in a random order would have changed the responses. Finally, thinking about one’s own death can be a challenging process.7 Perhaps 30 minutes was not enough time to imagine these potential futures.8 It would be informa-

INVITED COMMENTARY

Defibrillators, Deactivation, Decisions, and Dying

In a medical culture where death is often viewed as failure, clinicians and patients struggle to have high-quality discussions about deactivating an implantable cardioverter-defibrillator (ICD). The implications of this inaction are not trivial. In approximately half of hospices over the course of a year, patients dying of incurable disease will be shocked by their ICDs.3 Multiple societies have made recent calls for increased communication around ICD deactivation.2,3 However, exactly what form those conversations should take has yet to be determined.

In this issue, Dodson et al1 publish results from a survey of 95 patients with ICDs (70% response rate) regarding their preferences for ICD deactivation. They found that when faced with a series of 5 scenarios about deactivation, 71% of respondents answered “possibly” or “definitely yes” that they would want their ICD deactivated. The authors also report qualitative results demonstrating relatively poor understanding of the risks and benefits of the ICD.