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Patient Preferences for Deactivation of Implantable Cardioverter Defibrillators

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Introduction

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 in even in deleterious future health states including terminal cancer [4], constant dyspnea [5], or receipt of frequent shocks [5,6].

We examined preferences for ICD deactivation in the context of health outcomes such as functional and cognitive disability 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.

Methods

We recruited ICD patients ≥50 years of age 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 1/1/2006 and 12/31/2009. 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 one investigator (JD), and those consenting were administered a 20-minute telephone survey. The study was approved by the Yale Human Investigation Committee.

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The survey (Appendix 1) included two open-ended questions: “what do you feel are the (1) potential benefits and (2) potential harms of your ICD?” Responses were transcribed and later categorized by three investigators (JD, TF, RL), 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 five scenarios representing key domains of health [8] that strongly influence treatment preferences [7]. The scenarios were: (1) permanently unable to get out of bed, (2) permanent memory problems, (3) burden to family members, (4) prolonged mechanical ventilation (>1 month), (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 one scenario.

Results

Of 136 eligible patients contacted, 95 (70%) agreed to participate. Mean age was 71.4 ± 10.6 years, 28% were female, and 19% were nonwhite. The mean 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 (Table): restarting the heart (N=31), living longer (N= 27), improving quality of life (N=7), other (N=4: three thought the ICD prevented atrial fibrillation or stroke, one that it improved heart function). Sixty participants could not name a potential harm. The remaining categories were: receiving a shock (N=14), device malfunction (N=8), nuisance (N=5), complication (infection or bleeding) (N=2), inappropriate end-of-life shocks (N=2), other (N=4: one related to a phantom shock, three to unrealistic fears regarding harming the device [by lying down, touching the device, or falling]).

Sixty-seven (71%) participants wanted ICD deactivation in one 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 (Appendix 2). 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 one 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 [4–6]. One may be the age of our study sample, which consisted exclusively of older individuals (age ≥50). 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 of 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 [9], as 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.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table

Qualitative and Quantitative Results

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”.
“It’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”.

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 eight 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”.

Association of Patient Characteristics with ICD Deactivation Preference (N=95)

	Would deactivate N (%)	**P value**

Age	16 (70%)	0.91
≥80 (N=23)	51 (71%)	
<80 (N=72)		
Sex	22 (82%)	0.14
Female (N=27)	45 (66%)	
Male (N=68)		
Race	58 (75%)	0.03
White (N=77)	9 (50%)	
Nonwhite (N=18)		
Education	59 (72%)	0.44
≥12th grade (N=82)	8 (62%)	
<12th grade (N=13)		
Marital status	43 (74%)	0.33
Married (N=58)	24 (65%)	
Unmarried (N=37)		
Charlson score	37 (69%)	0.62
≥3 (N=54)	30 (73%)	
<3 (N=41)		
ICD implant duration	20 (61%)	0.12
≥5 years prior (N=33)	47 (76%)	
<5 years prior (N=62)		
Prior shock	16 (57%)	0.06
Yes (N=28)	51 (76%)	
No (N=67)		
IADL disability*	21 (88%)	0.03
Yes (N=24)	46 (65%)	
No (N=71)		
Depression (PHQ-2 ≥3)	7 (54%)	0.16
Yes (N=13)	60 (73%)	
No (N=82)		
Chronic pain	23 (77%)	0.37
Yes (N=30)	47 (68%)	
No (N=65)		
Mobility limitation†	21 (78%)	0.33
Yes (N=27)	46 (68%)	
No (N=68)		

* IADL (instrumental activity of daily living) disability = disability (any) in shopping, preparing meals, housekeeping, laundry, transportation, taking medications

† Mobility limitation = “health limits a lot” climbing one stairs or walking one block