Published in final edited form as:

Palliat Med. 2018 January ; 32(1): 156–163. doi:10.1177/0269216317718438.

Implantable cardioverter defibrillator knowledge and end-of-life device deactivation: A cross-sectional survey

Samantha M McEvedy¹, Jan Cameron², Eugene Lugg³, Jennifer Miller⁴, Chris Haedtke⁴, Muna Hammash⁵, Martha J Biddle⁴, Kyoung Suk Lee⁶, Justin A Mariani^{2,3,7}, Chantal F Ski⁸, David R Thompson⁸, Misook Lee Chung⁴, and Debra K Moser⁴

¹School of Psychology and Public Health, La Trobe University, Melbourne, VIC, Australia

²Department of Medicine, School of Clinical Sciences, Monash University, Melbourne, VIC, Australia

³St Vincent's Hospital Melbourne, Fitzroy, VIC, Australia

⁴College of Nursing, University of Kentucky, Lexington, KY, USA

⁵School of Nursing, University of Louisville, Louisville, KY, USA

⁶College of Nursing, Chungnam National University, Daejeon, South Korea

⁷Heart Centre, The Alfred Hospital, Melbourne, VIC, Australia

⁸Department of Psychiatry, The University of Melbourne, Melbourne, VIC, Australia

Abstract

Background—End-of-life implantable cardioverter defibrillator deactivation discussions should commence before device implantation and be ongoing, yet many implantable cardioverter defibrillators remain active in patients' last days.

Aim—To examine associations among implantable cardioverter defibrillator knowledge, patient characteristics and attitudes to implantable cardioverter defibrillator deactivation.

Design—Cross-sectional survey using the Experiences, Attitudes and Knowledge of End-of-Life Issues in Implantable Cardioverter Defibrillator Patients Questionnaire. Participants were classified as insufficient or sufficient implantable cardioverter defibrillator knowledge and the two groups were compared.

Setting/participants—Implantable cardioverter defibrillator recipients ($n = 270$, mean age 61 ± 14 years; 73% male) were recruited from cardiology and implantable cardioverter defibrillator clinics attached to two tertiary hospitals in Melbourne, Australia, and two in Kentucky, the United States.

Reprints and permissions: sagepub.co.uk/journalsPermissions.nav

Corresponding author: Samantha M McEvedy, School of Psychology and Public Health, La Trobe University, Melbourne, Victoria, 3086, Australia. s.mcevedy@latrobe.edu.au.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Results—Participants with insufficient implantable cardioverter defibrillator knowledge ($n = 77$, 29%) were significantly older (mean age 66 vs 60 years, $p = 0.001$), less likely to be Caucasian (77% vs 87%, $p = 0.047$), less likely to have received implantable cardioverter defibrillator shocks (26% vs 40%, $p = 0.031$), and more likely to have indications of mild cognitive impairment (Montreal Cognitive Assessment score < 24 : 44% vs 16%, $p < 0.001$). Insufficient implantable cardioverter defibrillator knowledge was associated with attitudes suggesting unwillingness to discuss implantable cardioverter defibrillator deactivation, even during the last days towards end of life ($p < 0.05$).

Conclusion—Implantable cardioverter defibrillator recipients, especially those who are older or have mild cognitive impairment, often have limited knowledge about implantable cardioverter defibrillator deactivation. This study identified several potential teachable moments throughout the patients' treatment trajectory. An interdisciplinary approach is required to ensure that discussions about implantable cardioverter defibrillator deactivation issues are initiated at appropriate time points, with family members ideally also included.

Keywords

Implantable cardioverter defibrillator; knowledge; attitudes; device deactivation; end-of-life discussions

Introduction

The delivery of implantable cardioverter defibrillator (ICD) shocks to patients at end of life can be a distressing experience for both patients and caregivers.^{1,2} One in three ICD recipients experiences multiple shocks in their last days of life, which can be painful and futile, prolonging the dying process and denying patients a comfortable and dignified death.^{1,3} Due to delays in deactivation, ICD shock therapy often continues even after the patient has a formal written 'do not resuscitate' order.⁴ Therefore, it is important that healthcare professionals who are involved in the care of ICD recipients or in providing end-of-life care be well informed and able to discuss ICD deactivation issues with patients and their families.

Deactivation of an ICD does not lead to immediate death but does prevent the delivery of defibrillation shocks which have the potential to resuscitate the patient if they experience a fatal heart rhythm at end of life.^{5,6} Planned deactivation of an ICD is a simple, non-invasive procedure that can be carried out by a technician.⁷ In an emergency situation, placing a strong magnet on the skin will suspend shock delivery without interfering with the device's ability to function as a pacemaker.⁷ For a patient nearing end of life, ICD deactivation allows a fatal heart rhythm to remain uncorrected, leading to a naturally occurring death.⁸ Adequately informing patients about this topic prior to placement has been shown to reduce anxiety.⁹

Recently, investigators have shown that ICD recipients are not adequately informed about ICD deactivation and discussions about ICD deactivation rarely occur.^{8,10,11} This may, in part, be due to variation in patients' wishes^{11–14} or reticence on behalf of healthcare providers to discuss ICD deactivation.^{2,10,15,16} Expert consensus statements recommend that ICD deactivation discussions should occur before implantation and continue throughout the

patient's illness trajectory.^{6,7,17,18} In the absence of such discussions, patients and their families lack the knowledge on which to make informed decisions.^{4,17}

The 'Experiences, Attitudes and Knowledge of End-of-Life Issues in Implantable Cardioverter Defibrillator Patients Questionnaire' (EOL-ICDQ) was developed to capture the perceptions of ICD recipients in relation to ICD and end-of-life issues.^{11,17,19} Previous research suggests that a lack of patient knowledge and understanding about the role and function of ICDs may increase reluctance to engage in discussion about ICD deactivation at end of life.^{2,8,16} Therefore, the aims of this study were to: (1) describe patient knowledge regarding their ICD, (2) identify patient characteristics associated with insufficient ICD knowledge and (3) examine associations between ICD knowledge and willingness to discuss issues relating to ICD deactivation.

Materials and methods

This cross-sectional study involved a structured survey given to ICD recipients from Australia and the United States. The study received ethical approval from hospital and University review boards in Australia (215/15; 42-2015; 2015-165R) and the United States (13-0993; 13.0666). Data were collected between July 2015 and July 2016.

Participants

Participants were recruited from cardiology and ICD clinics attached to tertiary hospitals in Melbourne and Kentucky. Eligibility criteria were the following: ICD insertion >12 months, English speaking, a Montreal Cognitive Assessment (MoCA) score of 20 or higher, not institutionalised (e.g. not residing in a nursing home or prison) and not awaiting urgent inpatient cardiac transplantation.

Procedures

Potential participants were identified by a research nurse working in conjunction with nurses at hospital ICD clinics. The researcher approached participants while waiting for their cardiology appointment whereupon the study's purpose, eligibility criteria, ethics approval and consent process were explained. Participants were screened for eligibility and any questions were answered before written consent was obtained. Participants were given a hard copy of the survey to take home to complete at their leisure and return by post in a reply-paid envelope with an alternative option to complete the survey online or in the clinic. The majority of participants (>90%) opted to take the survey home to complete and return by post. Although participants were given this cooling off period, the response rate was 82% in Australia and 94% in the United States.

Measures

The full survey consisted of sociodemographic questions, the EOL-ICDQ, and the MoCA. Sociodemographic questions included age, gender, ethnicity, household status, level of education and clinical variables (e.g. self-reported general health, heart disease and co-morbidities, year of first ICD and experience of ICD shocks).

The MoCA was administered by the research nurse working under the supervision of a psychologist and used to screen participants for eligibility (MoCA score <20 excluded) at the hospital clinic before the participant was given the survey to self-complete at a time which suited them. The MoCA assesses cognitive function in six domains including memory (recall and working), visuospatial, executive function, attention/concentration, language and orientation. MoCA scores can range from 0 to 30, with higher scores reflecting better cognitive performance.²⁰ In this study, mild cognitive impairment (MCI) was defined as MoCA score <24 as this has been shown to have high specificity (83% for multiple domain MCI) and improved sensitivity (52%) compared to a cut-off score <26 in people with cardiovascular disease.²¹

The EOL-ICDQ is a 39-item instrument that was developed in Europe and measures participants' knowledge, experiences and attitudes about their ICD, including attitudes about deactivation of the ICD at end of life and desire to have discussions about end-of-life issues. Validity (as assessed by experts and patients in the research group and participants in the pilot study) and test-retest reliability (in which most items showed moderate to good reproducibility with kappa >0.4) of the Swedish version of the EOL-ICDQ were found to be sufficient.¹⁹ A translation/back translation from Swedish to English was performed and an English version of the EOL-ICDQ was found to have sound face and content validity.¹⁹

This is the first study to utilise the English language version of the EOL-ICDQ in an international, English-speaking sample of ICD recipients. Therefore, we tested scale reliability and found that overall Cronbach's alpha across all 39 items was 0.65.

In this study, we used the ICD knowledge and attitudes to discussions components of the EOL-ICDQ. The knowledge component consists of 11 'True'/'False'/'Don't know' items which cover practical, functional and ethical domains of knowledge relating to ICD deactivation and end-of-life issues. Consistent with previous research,¹⁷ the 11 EOL-ICDQ knowledge variables were recoded as either correct (1) or incorrect/don't know/not answered (0). ICD knowledge scores were calculated for each participant and ranged from 0 to 11, where higher scores denote higher levels of knowledge. Attitudes about when healthcare providers should raise questions relating to ICD deactivation were captured in 10 'Agree'/'Don't agree' items.

Data analyses

Data were analysed using SPSS V22. Data distribution characteristics were assessed for all variables; ICD knowledge score was slightly negatively skewed (-0.466) and leptokurtic (-0.697). Thus, to conduct the comparisons designated in the specific aims, the ICD knowledge score was categorised as either sufficient or insufficient. Consistent with past research,¹⁷ the lowest 25th percentile score was used as the cut-off indicating insufficient knowledge. Key variables, including ICD knowledge scores, were compared between the United States and Australia and found to be similar; therefore, samples from the two countries were combined in further analyses. Regardless of healthcare infrastructure or economic basis for healthcare, the issues relevant to decision-making regarding end-of-life care for ICD patients are related to patient self-determination. In addition, universally, guidelines for ICD patients are the same regarding discussions by healthcare providers.

Sociodemographic and clinical characteristics of the insufficient and sufficient knowledge groups were compared using chi-square tests or independent sample T-tests as appropriate. A partial correlation coefficient was calculated for ICD knowledge and MoCA scores controlling for age. Attitudes to ICD deactivation discussions were compared for the insufficient and sufficient knowledge groups using chi-square tests. All hypothesis tests were two-sided and *p*-values of less than 0.05 were considered statistically significant.

Results

Participant characteristics

In total, 270 participants (mean age, 61 ± 14 years; 73% male) were included in the analyses. Mean time since ICD insertion was 7 ± 4 years and 97 participants (36%) had experienced one or more ICD shocks. Demographic and clinical characteristics of all participants are described (Table 1).

Patient knowledge regarding their ICD

Of the 270 participants, only 7 (3%) provided the correct answer for all 11 statements. Median number of correct responses was 7 (interquartile range, 4–8), and this was similar between the United States and Australia at a total level and also when statements were grouped into practical, ethical and functional knowledge domains. Item statistics for all ICD knowledge statements are provided (Table 2). The three items that participants were most likely to answer correctly were ‘when an ICD’s shocks are turned off the heart stops beating’ (which is False), ‘when the ICDs shocks have been turned off, they can’t be turned on again’ (False) and ‘in order to turn off the ICD’s shocks reprogramming can be performed by an external programmer’ (True) (Table 2). The three items participants were least likely to answer correctly were ‘an ICD always delivers shocks in connection with end of life’ (False), ‘when the ICD’s shocks are turned off, the pacemaker function in the ICD is also deactivated’ (False) and ‘when an ICDs battery voltage is beginning to wear, even the ICDs functioning worsens’ (False) (Table 2).

Patient characteristics associated with insufficient ICD knowledge

Using the 25th percentile as a cut-off point, which equated to 4 out of 11 correct responses, 77 (29%) participants were classified as having insufficient ICD knowledge. Compared to those with sufficient knowledge, insufficient ICD knowledge was associated with older age (mean: 66 vs 60 years, $t = 3.399$, $p = 0.001$), being non-Caucasian and not having experienced ICD shock therapy (Table 1). Insufficient ICD knowledge was also associated with MCI as measured by MoCA score <24 (Table 1). A significant correlation between ICD knowledge and MoCA scores persisted after controlling for age (partial $r = 0.232$, $p < 0.001$).

Associations between ICD knowledge and willingness to discuss ICD deactivation issues

Insufficient ICD knowledge was associated with greater unwillingness to discuss issues relating to ICD deactivation with clinicians. This was demonstrated by a significantly higher percentage of those with insufficient ICD knowledge agreeing that they ‘do not wish to have such a conversation’ and a significantly lower percentage agreeing that healthcare providers

should raise the question of what is involved in ICD deactivation ‘towards end of life, during the last days’ (Table 3).

The majority (93%) of participants, including those with insufficient ICD knowledge, agreed with one or more of the suggested circumstances in which healthcare professionals might raise the issue of ICD deactivation. Three quarters (72%) of participants agreed that deactivation issues should be raised in connection with ICD implantation, while the greatest number (82%) said they would raise the question themselves if they felt the need to (Table 3). Other potential teachable moments at which the majority of participants endorsed the idea of healthcare professionals initiating discussions about ICD deactivation at end of life were in the last days towards end of life, if the heart disease deteriorates, if they are repeatedly hospitalised, have one or multiple shocks or are suffering from a disease with a poor prognosis (Table 3). Furthermore, over half (55%) agreed that ICD deactivation should be discussed routinely at ICD clinic appointments.

Discussion

The key findings of this study were that ICD recipients often lacked knowledge about the functioning of their ICD and issues relating to device deactivation at end of life. People with insufficient ICD knowledge were less likely to be Caucasian or to have received ICD shocks and were significantly older. A novel finding of this study was that insufficient knowledge was associated with an indication of MCI with the correlation between ICD knowledge and cognition as measured by MoCA score persisting after accounting for age. Insufficient ICD knowledge was associated with attitudes suggesting unwillingness to discuss ICD deactivation, even at end of life in the last days.

Overall, the study’s findings relating to patients’ frequent poor understanding and lack of knowledge in relation to ICD are in line with the findings of other research in this area.^{3,10,12,17} Improved communication and patient education to address the issue of insufficient understanding of the practical, functional and ethical issues relating to ICD deactivation at end of life appear to be required.^{3,12} The question of who should provide such education remains of interest. It has been noted that patients prefer their physicians to inform them about options for device deactivation, with little mention of nurses performing this role.^{12,22} However, nurses with advanced care skills (e.g. electrophysiology, heart failure, palliative care) may be well placed to have open communication and discussion with patients about their end-of-life preferences, including ICD deactivation.²³ Since many ICDs remain active during patients’ last days,^{1,2} an interdisciplinary approach is required in which all healthcare professionals involved in end-of-life care provision need to be well informed about ICD deactivation issues and able to discuss these with patients and their families.²⁴

Our findings in relation to ICD knowledge scores are similar to those in the Swedish cohort.¹⁷ The 25th percentile cut-off in our study was 4 compared to 5 out of 11 in Sweden. This may indicate slightly better ICD knowledge among Swedish participants, particularly since average age was 5 years younger in our sample. There may be other cultural differences in terms of knowledge and attitudes relating to ICD deactivation. In our study, there was an association between racial background and ICD knowledge, with Caucasian participants

more likely to have sufficient knowledge. This may be related to differences in health literacy or cultural differences in attitudes towards end of life.

Consistent with other research,^{17,25} participants who had received one or more ICD shocks were more likely to have sufficient ICD knowledge. This may be due to patients' interpretation of a shock as signifying poor health and worsening prognosis,²⁶ or the experience of ICD shock resulting in the need for more information, thereby creating a teachable moment at which patients are more receptive and see such knowledge as more relevant to them. Some studies have reported experiences of ICD shocks being associated with more favourable attitudes towards deactivation while others found many ICD recipients would choose to keep their device active even if experiencing frequent shocks.¹² While experience of ICD shock may create a teachable moment when patients and family members are more open to receiving information about the functioning of the ICD and the circumstances under which device deactivation might be considered in relation to end of life, some patients do not receive ICD shocks at all. Therefore, discussion of ICD deactivation issues should be considered in a range of circumstances, not only when patients experience ICD shock therapy.

Our finding of an association between insufficient ICD knowledge and older age is consistent with results from Sweden.¹⁷ However, we further found an association between insufficient ICD knowledge and MCI. Interestingly, although older age is a known risk factor for MCI,²⁷ the correlation between cognition and ICD knowledge persisted after controlling for age. ICD implantation has been associated with neuropsychological impairments in some patients up to 12 months after surgery.²⁸ In qualitative research, patients have expressed the need for ICD deactivation discussions to occur before they experience serious cognitive decline.²⁴ Nevertheless, it is generally accepted that, when possible, the patient's spouse or caregiver should be involved in discussions about issues surrounding deactivation of ICD at end of life.^{29,30}

Several studies have indicated that discussions about ICD deactivation rarely occur.^{8–11} Although the predominant response from participants in our study was that they would raise the issue of device deactivation themselves, our findings also demonstrate that there are a number of teachable moments at which ICD recipients are open to receiving information about ICD deactivation and end-of-life issues.^{9,11,31} Although clinicians may be uneasy raising the topic of ICD deactivation,^{15,16} our study provides further evidence that the majority of patients support provider initiation of such discussions.¹² It has previously been noted that patients generally prefer to have discussions about ICD deactivation and end of life when their health status worsens, rather than during regular appointments.¹¹ This observation was confirmed by our study, in which just over half of participants agreed that these issues should be raised at regular clinic visits. However, efforts to normalise such discussions and improve ICD knowledge may be beneficial for patients, providing them with information to guide them in planning, preparing and discussing their wishes regarding end of life with their families.³² This is in line with the conclusions others have drawn regarding the need for clinicians to talk to patients and their families about ICD functionality and deactivation at appropriate opportunities.¹² It is also consistent with recommendations that patients should have an opportunity to discuss ICD-related issues, including deactivation, at

routine appointments while ensuring that this is not forced on patients who clearly state that they do not wish to talk about it.⁷

Despite efforts to discuss ICD deactivation issues earlier in the patient's illness trajectory, clinicians involved in the provision of end-of-life care may still encounter ICD recipients who have limited knowledge about their ICD. In such cases, it is worth noting that ICD deactivation, with the intention to relieve device related burden, is legal following receipt of informed consent from the patient or, if the patient is unable to do so due to incapacity, their next of kin.⁹

Limitations

This study had a number of limitations. As with all observational studies, the cross-sectional survey design does not allow us to draw conclusions about the causal relationship between ICD knowledge and other variables. The sample was limited to ICD recipients from two hospitals in Melbourne, Australia, and two in Kentucky, the United States. Therefore, results may lack generalisability to other settings. There was a risk of selection bias in the sample whereby patients more ready to discuss ICD issues may have been more willing to participate. The English language version of the EOL-ICDQ has not been fully validated, though we did check internal validity of the questionnaire and found it to be satisfactory. The sample size was not large enough to enable us to analyse more than two knowledge groups. Therefore, we chose the 25th percentile to denote insufficient knowledge because there was a precedent for this approach and results could be compared to previous research. During our preliminary analysis, before we had sufficient sample size to use the 25th percentile, we analysed the data using the 50th percentile as the cut-off and found similar results to those published here. Cardiac conditions were based on self-report data. Medical record checks were performed for 139 participants for whom the positive predictive value of self-reported heart condition was 78% for heart failure, 70% for atrial fibrillation and 48% for myocardial infarction.

Conclusion

ICD recipients, especially those who are older or have MCI, often have limited knowledge relating to ICD deactivation. The study identified a number of potential teachable moments, such as device implantation, routine clinic appointments, hospitalisation, the device delivering shock therapy, deterioration of heart disease or if diagnosed with a terminal illness as well as near end of life, at which most patients consider it appropriate for clinicians to initiate discussions with patients, which should ideally also include family members, about issues relating to ICD deactivation.

Acknowledgments

The authors acknowledge the contribution of Mr Georgios Zisis in recruiting participants and the valued collaboration with clinical partners, including cardiologists and nurses.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship and/or publication of this article: In Australia, this study received funding from a faculty grant provided by Australian Catholic

University (ACU). In the United States, the study was funded by a research professor award from the University of Kentucky and an internal initiative grant from the University of Louisville.

Biographies

Samantha Mcevedy, Australian Catholic University

Jan Cameron, Australian Centre for Heart Health

Jennifer Miller, University of Kentucky

Christine Haedtke, Indiana University-Purdue University Indiana...

References

1. Kinch Westerdahl A, Sjoblom J, Mattiasson AC, et al. Implantable cardioverter-defibrillator therapy before death: high risk for painful shocks at end of life. *Circulation*. 2014; 129:422–429. [PubMed: 24243857]
2. Russo JE. Deactivation of ICDs at the end of life: a systematic review of clinical practices and provider and patient attitudes. *Am J Nurs*. 2011; 111:26–35.
3. Groarke J, Beirne A, Buckley U, et al. Deficiencies in patients' comprehension of implantable cardioverter defibrillator therapy. *Pacing Clin Electrophysiol*. 2012; 35:1097–1102. [PubMed: 22734654]

4. Westerdahl AK, Sutton R, Frykman V. Defibrillator patients should not be denied a peaceful death. *Int J Cardiol.* 2015; 182:440–446. [PubMed: 25597981]
5. Gadoud A, Jenkins SM, Hogg KJ. Palliative care for people with heart failure: summary of current evidence and future direction. *Palliat Med.* 2013; 27:822–828. [PubMed: 23838375]
6. Padeletti L, Arnar DO, Boncinelli L, et al. EHRA expert consensus statement on the management of cardiovascular implantable electronic devices in patients nearing end of life or requesting withdrawal of therapy. *Europace.* 2010; 12:1480–1489. [PubMed: 20675674]
7. Pitcher D, Soar J, Hogg K, et al. Cardiovascular implanted electronic devices in people towards the end of life, during cardiopulmonary resuscitation and after death: guidance from the Resuscitation Council (UK), British Cardiovascular Society and National Council for Palliative Care. *Heart.* 2016; 102(Suppl. 7):A1–A17. [PubMed: 27277710]
8. Niewald A, Broxterman J, Rosell T, et al. Documented consent process for implantable cardioverter-defibrillators and implications for end-of-life care in older adults. *J Med Ethics.* 2013; 39:94–97. [PubMed: 23139392]
9. Clark AM, Jaarsma T, Strachan P, et al. Effective communication and ethical consent in decisions related to ICDs. *Nat Rev Cardiol.* 2011; 8:694–705. [PubMed: 21788961]
10. Lewis KB, Stacey D, Matlock DD. Making decisions about implantable cardioverter-defibrillators from implantation to end of life: an integrative review of patients' perspectives. *Patient.* 2014; 7:243–260. [PubMed: 24668214]
11. Thylén I, Moser DK, Chung ML, et al. Are ICD recipients able to foresee if they want to withdraw therapy or deactivate defibrillator shocks? *IJC Heart Vessel.* 2013; 1:22–31.
12. Hill L, McIlpatrick S, Taylor B, et al. Patients' perception of implantable cardioverter defibrillator deactivation at the end of life. *Palliat Med.* 2014; 29:310–323. [PubMed: 25239128]
13. Pedersen SS, Chaiting R, Szili-Torok T, et al. Patients' perspective on deactivation of the implantable cardioverter-defibrillator near the end of life. *Am J Cardiol.* 2013; 111:1443–1447. [PubMed: 23490027]
14. Herman D, Stros P, Curila K, et al. Deactivation of implantable cardioverter-defibrillators: results of patient surveys. *Europace.* 2013; 15:963–969. [PubMed: 23447573]
15. Low J, Pattenden J, Candy B, et al. Palliative care in advanced heart failure: an international review of the perspectives of recipients and health professionals on care provision. *J Card Fail.* 2011; 17:231–252. [PubMed: 21362532]
16. Mitar M, Alba AC, MacIver J, et al. Lost in translation: examining patient and physician perceptions of implantable cardioverter-defibrillator deactivation discussions. *Circ Heart Fail.* 2012; 5:660–666. [PubMed: 22991406]
17. Stromberg A, Fluor C, Miller J, et al. ICD recipients' understanding of ethical issues, ICD function, and practical consequences of withdrawing the ICD in the end-of-life. *Pacing Clin Electrophysiol.* 2014; 37:834–842. [PubMed: 24483943]
18. Epstein AE, DiMarco JP, Ellenbogen KA, et al. 2012 ACCF/AHA/HRS focused update incorporated into the ACCF/AHA/HRS 2008 guidelines for device-based therapy of cardiac rhythm abnormalities: a report of the American College of Cardiology Foundation/American Heart Association Task Force on Practice Guidelines and the Heart Rhythm Society. *Circulation.* 2013; 127:e283–e352. [PubMed: 23255456]
19. Thylen I, Wenemark M, Fluor C, et al. Development and evaluation of the EOL-ICDQ as a measure of experiences, attitudes and knowledge in end-of-life in patients living with an implantable cardioverter defibrillator. *Eur J Cardiovasc Nurs.* 2014; 13:142–151. [PubMed: 24298191]
20. Nasreddine ZS, Phillips NA, Bedirian V, et al. The Montreal Cognitive Assessment, MoCA: a brief screening tool for mild cognitive impairment. *J Am Geriatr Soc.* 2005; 53:695–699. [PubMed: 15817019]
21. McLennan SN, Mathias JL, Brennan LC, et al. Validity of the Montreal Cognitive Assessment (MoCA) as a screening test for mild cognitive impairment (MCI) in a cardiovascular population. *J Geriatr Psychiatry Neurol.* 2011; 24:33–38. [PubMed: 21156989]
22. Kirkpatrick JN, Gottlieb M, Sehgal P, et al. Deactivation of implantable cardioverter defibrillators in terminal illness and end of life care. *Am J Cardiol.* 2012; 109:91–94. [PubMed: 21943937]

23. Hupcey JE, Kitko L, Alonso W. Palliative care in heart failure. *Crit Care Nurs Clin North Am*. 2015; 27:577–587. [PubMed: 26567500]
24. Strachan PH, Carroll SL, De Laat S, et al. Patients' perspectives on end-of-life issues and implantable cardioverter defibrillators. *J Palliat Care*. 2011; 27:6–11. [PubMed: 21510126]
25. Raphael CE, Koa-Wing M, Stain N, et al. Implantable cardioverter- defibrillator recipient attitudes towards device deactivation: how much do patients want to know? *Pacing Clin Electrophysiol*. 2011; 34:1628–1633. [PubMed: 21955046]
26. Sears SF, Kirian K. Shock and patient-centered outcomes research: is an ICD shock still a critical event? *Pacing Clin Electrophysiol*. 2010; 33:1437–1441. [PubMed: 20727093]
27. Petersen RC, Caracciolo B, Brayne C, et al. Mild cognitive impairment: a concept in evolution. *J Intern Med*. 2014; 275:214–228. [PubMed: 24605806]
28. Hallas CN, Burke JL, White DG, et al. A prospective one year study of changes in neuropsychological functioning following implantable cardioverter defibrillator surgery. *Circ Arrhythm Electrophysiol*. 2010; 3:170–177. [PubMed: 20197542]
29. Fluor C, Bolse K, Stromberg A, et al. Spouses' reflections on implantable cardioverter defibrillator treatment with focus on the future and the end-of-life: a qualitative content analysis. *J Adv Nurs*. 2014; 70:1758–1769. [PubMed: 24321029]
30. Lee MC, Sulmasy DP, Gallo J, et al. Decision-making of patients with implantable cardioverter-defibrillators at end of life: family members' experiences. *Am J Hosp Palliat Care*. 2017; 34:518–523. [PubMed: 27034436]
31. MacIver J, Tibbles A, Billia F, et al. Patient perceptions of implantable cardioverter-defibrillator deactivation discussions: a qualitative study. *SAGE Open Med*. 2016; 4 2050312116642693.
32. Whellan DJ, Goodlin SJ, Dickinson MG, et al. End-of-life care in patients with heart failure. *J Card Fail*. 2014; 20:121–134. [PubMed: 24556532]

What is already known about the topic?

- Discussions about implantable cardioverter defibrillator (ICD) deactivation in relation to end of life should commence before device implantation and continue throughout the patient's illness.
- Lack of knowledge makes it difficult for patients and their families to make informed decisions about ICD deactivation at end of life.

What this paper adds?

- ICD recipients often have insufficient knowledge about their ICD and this is more likely among older participants, those with mild cognitive impairment and those who have not received ICD shocks.
- Lack of knowledge is also associated with unwillingness to discuss ICD deactivation, even in the last days towards end of life.

Implications for practice, theory or policy

- An interdisciplinary approach is required to ensure clinicians initiate discussions about ICD deactivation at end of life during potential teachable moments throughout the patient's treatment trajectory.
- Family members should be included in discussions when possible with a view to enabling them to make informed decisions about device deactivation to avoid delivery of unnecessary shocks at end of life.

Table 1

Sample profile and characteristics associated with ICD Knowledge.

	ICD knowledge level			Two-tailed <i>p</i>
	Total sample <i>n</i> (%)	Insufficient <i>n</i> (%)	Sufficient <i>n</i> (%)	
Total <i>n</i>	270	77	193	
Location				
USA	197 (73)	59 (77)	138 (72)	0.392
Australia	73 (27)	18 (23)	55 (28)	
Demographics				
Male	196 (73)	51 (66)	145 (75)	0.139
Age ≥ 65 years	126 (47)	48 (62)	78 (40)	0.001 [*]
Lives alone	61 (23)	17 (22)	44 (23)	0.898
Completed high school	197 (73)	54 (70)	143 (74)	0.701 [†]
MoCA <24 (mild cognitive impairment)	64 (24)	34 (44)	30 (16)	<0.001 [*]
Ethnicity				
Caucasian	226 (84)	59 (77)	167 (87)	0.047 [*]
African American/Asian/Hispanic/Indigenous/Other	44 (16)	18 (23)	26 (14)	
Self-reported heart disease diagnosis				
Atrial fibrillation	114 (42)	25 (32)	89 (46)	0.103
Angina (pectoris)	48 (18)	10 (13)	38 (20)	0.428
Myocardial infarction	72 (27)	21 (27)	51 (26)	0.776
Heart failure	169 (63)	46 (60)	123 (64)	0.641
Other heart disease	19 (7)	4 (5)	15 (8)	0.732
Rating of overall health				
Poor/very poor	62 (23)	14 (18)	48 (25)	0.217 [†]
Fairly/good/very good	202 (75)	62 (81)	140 (73)	
Received ICD shocks				
No	169 (63)	55 (71)	114 (59)	0.026 ^{*,†}
Yes, once	40 (15)	12 (16)	28 (15)	
Yes, more than once	57 (21)	8 (10)	49 (25)	

ICD: implantable cardioverter defibrillator; MoCA: Montreal cognitive assessment.

Missing data (declined to answer) not shown.

^{*} Significant differences with alpha of 0.05.[†] Missing data excluded from chi-square test.

Table 2

Item statistics for variables relating ICD knowledge.

Knowledge statement	Correct <i>n</i> (%)	Incorrect <i>n</i> (%)
1. In order to turn off the shocks in an ICD, the ICD must be removed by surgery (P)	166 (61)	104 (39)
2. When the ICDs shocks have been turned off, they can't be turned on again (P)	170 (63)	100 (37)
3. When an ICDs shocks are turned off, the heart stops beating (E)	217 (80)	53 (20)
4. An ICDs shocks can be turned off without my, or my next-of-kin's knowledge (E)	167 (62)	103 (38)
5. To turn off the shocks in an ICD is the same as active euthanasia (E)	165 (61)	105 (39)
6. In order to turn off the ICDs shocks, a temporary deactivation can be done via a magnet (P)	124 (46)	146 (54)
7. In connection with the shock, the shock is also transferred to those persons having direct bodily contact (P)	124 (46)	146 (54)
8. When an ICDs battery voltage is beginning to wear, even the ICD's functioning worsens (F)	114 (42)	156 (58)
9. An ICD always delivers shocks in connection with end-of-life (P)	104 (39)	166 (61)
10. In order to turn off the ICDs shocks a reprogramming can be performed by an external programmer (P)	184 (68)	86 (32)
11. When the ICDs shocks are turned off, the pacemaker function in the ICD is also deactivated (F)	108 (40)	163 (60)

ICD: implantable cardioverter defibrillator; P: practical domain; E: ethical domain; F: functional domain.

Percentages based on total sample ($n = 270$). Letters in parenthesis after statement indicate knowledge domain. Correct response 'False' for all except statements 6 and 10.

Table 3

When healthcare professionals should raise the question of ICD deactivation.

	ICD knowledge level			Two-tailed <i>p</i>
	Total sample	Insufficient 4	Sufficient 5	
	Agree, <i>n</i> (%)	Agree, <i>n</i> (%)	Agree, <i>n</i> (%)	
Total <i>n</i>	270	77	193	
1. I do not wish to have such a conversation	113 (42)	37 (48)	76 (39)	0.050 *
2. I myself will raise the question when I feel the need to	221 (82)	58 (75)	163 (84)	0.557
3. In connection with the ICD implantation	195 (72)	51 (66)	144 (75)	0.506
4. If I receive a shock	195 (72)	54 (70)	141 (73)	0.211
5. If I have multiple shocks	206 (76)	53 (69)	153 (79)	0.858
6. Upon repeatedly being hospitalised due to recurring heart problems	205 (76)	53 (69)	152 (79)	0.964
7. If I am suffering from a disease with a poor prognosis (e.g. cancer)	199 (74)	50 (65)	149 (77)	0.566
8. Routinely upon return visits to the ICD clinic	149 (55)	43 (56)	106 (55)	0.211
9. If my heart disease, the reason for the ICD treatment, deteriorates	211 (78)	54 (70)	157 (81)	0.562
10. Towards end of life, during the last days	213 (79)	50 (65)	163 (84)	0.022 *

ICD: implantable cardioverter defibrillator.

Missing data excluded from chi-square tests.

* Significant differences with alpha of 0.05. In all, 93% of participants agreed to at least one of circumstances numbered 3–10.