

Trends in time in the management of the implantable cardioverter defibrillator in the last phase of life: a retrospective study of medical records

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Abstract

Background: The implantable cardioverter defibrillator (ICD) might give unwanted shocks in the last month of life. Guidelines recommend deactivation of the ICD prior to death.

Aims: The aims of this study were to examine trends in time (2007–2016) in how and when decisions are made about ICD deactivation, and to examine patient- and disease-related factors which may have influenced these decisions. In addition, care and ICD shock frequency in the last month of life of ICD patients are described.

Methods: Medical records of a sample of deceased patients who had their ICD implanted in 1999–2015 in a Dutch university ($n = 308$) or general ($n = 72$) hospital were examined.

Results: Median age at death was 71 years, and 88% were male. ICD deactivation discussions increased from 6% for patients who had died between 2007 and 2009 to 35% for patients who had died between 2013 and 2016. ICD deactivation rates increased in these periods from 16% to 42%. Presence of do-not-resuscitate (DNR) orders increased from 9% to 46%. Palliative care consultations increased from 0% to 9%. When the ICD remained active, shocks were reported for 7% of patients in the last month of life. Predictors of ICD deactivation were the occurrence of ICD deactivation discussions after implantation (OR 69.30, CI 26.45–181.59), DNR order (OR 6.83, CI 4.19–11.12), do-not-intubate order (OR 6.41, CI 3.75–10.96), and palliative care consultations (OR 8.67, CI 2.76–27.21)

Conclusion: ICD deactivation discussions and deactivation rates have increased since 2007. Nevertheless, ICDs remain active in the majority of patients at the end of life, some of whom experience shocks.

Keywords

Decision-making, defibrillators, implantable cardioverter defibrillator, withholding treatment, terminal care, retrospective studies, incidence

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Introduction

The implantable cardioverter defibrillator (ICD) is effective in terminating life-threatening cardiac arrhythmias by giving electric shocks.¹ When death is imminent due to irreversible terminal illness, shocks might be unwanted and can be a factor of distress to the patient and his or her family that disturbs the dying process.²

A recent integrated review using a systematic approach shows that ICD shocks occur rather frequently on the last day of life, ranging from 24% to 33% in patients who die nonsuddenly up to 41–68% in patients who die suddenly.² However, 7 of 13 studies in this review were conducted two decades or more ago, and studies were mainly based on patients with a secondary prevention indication, who are more prone to experiencing shocks due to their cardiac history.³

Important developments in ICD management have taken place. First, international expert consensus statements on the management of the ICD in the last phase of life have been published.^{1,4–6} In these statements it is discussed that shocks in the last phase of life may be physically and psychologically stressful, and it is recommended to deactivate the ICD at the end of a patient's life.¹ It is also recommended that professional caregivers have early and recurring discussions on the possibility and desirability of deactivating the ICD. These statements might have established an increase in ICD deactivation discussions and actual deactivation. Second, ICD programming has been further optimized. A longer detection time and a higher rate cutoff have shown good results in reducing the number of inappropriate shocks.^{7,8} This might have established a decrease in patients receiving shocks at the end of life.

The aims of this study were to:

1. Examine the decision-making process concerning ICD deactivation and to examine patient- and disease-related factors influencing the decision to deactivate.
2. Describe the care and ICD shock frequency in the last month of life of ICD patients, in particular the presence of do-not-resuscitate (DNR) and do-not-intubate (DNI) orders and the involvement of palliative care teams.

For both questions we will describe the trends in time (periods 2007–2009, 2010–2012, and 2013–2016).

Methods

Patients and setting

Patients older than 18 years of age who had an ICD implanted in a large Dutch university hospital or in a general hospital and who died between 2007 and 2016 were

eligible for inclusion in the study. In the university hospital, a total of 544 patients with an ICD had died in the specified time period. These patients had their first ICD implanted between 1999 and 2015. Medical records of 25 deceased patients per year of implantation were randomly selected to be assessed for this study in order to obtain a representative sample that covered all years of implantation. If there were less than 25 deceased patients for an implantation year, all patients were included. A total of 308 patients in the university hospital were eventually included. In the general hospital, 72 patients had died. These patients had their ICD implanted between 2002 and 2015 and all were included.

Data collection

Data were collected by AB, RS, and AD from three sources:

1. ICD registries in both hospitals contained clinical information, demographics, and ICD-related information such as indication for implantation, categorized as primary (implantation in patients with elevated risk of arrhythmias or cardiac death) or secondary prevention (implantation in patients who already experienced life-threatening arrhythmias or aborted cardiac death),³ implantation date, type of ICD, and occurrence of shocks in the last month of life, categorized as appropriate (shock for ventricular fibrillation or ventricular tachycardia) or inappropriate (any other shock).
2. From the electronic and paper medical records we extracted the following data: the number and timing of ICD deactivation discussions, the presence of DNR and DNI orders, consultations with palliative care teams (both hospitals had such a team), reasons for consultation, occurrence and characteristics of ICD deactivation, and occurrence and timing of shocks. A checklist was developed and pilot tested in 10 patients by RS and AB.
3. If a patient had died outside hospital, we contacted the patient's general practitioner by telephone to collect data on the cause and place of death, whether or not the ICD was deactivated preceding death, and the occurrence of shocks in the last month of life.

Cause of death was classified by RS and DT in four categories, using an adapted version of the classification schemes of Hinkle and Thaler and Epstein et al.:^{9,10} *sudden cardiac death* – cardiac death that occurs within 1 h after the onset of new symptoms; *nonsudden cardiac death* – cardiac death that occurs more than 1 h after the onset of new symptoms; *noncardiac death* – death from other causes; and *unknown*. Our study conforms with the principles outlined in the Declaration of Helsinki.¹¹ Approval of

the local ethical committee (METC-2016-453) was obtained before starting the data collection.

Data analysis

Descriptive statistics were used to summarize demographic data. Mean scores and standard deviations were calculated for normally distributed data and medians and interquartile ranges (IQRs) for non-normally distributed data. Differences in medians between patients dying during 2007–2009, 2010–2012, and 2013–2016 were examined with Kruskal–Wallis tests. Categorical variables were compared with the Pearson Chi-square test, using a Bonferroni correction when appropriate. Differences between the two hospitals participating in this study were explored with Pearson Chi-square tests. Logistic regression analyses were conducted for the variables that were expected to possibly predict deactivation of the ICD:¹² age, gender, New York Heart Association (NYHA) classification, myocardial infarction, diabetes mellitus, chronic kidney disease, left ventricular ejection fraction (LVEF), indication for ICD implantation (primary vs. secondary prevention), occurrence of ICD discussion (no discussion vs. discussion before implantation vs. discussion after implantation), occurrence of palliative care team consultation (yes vs. no), presence of DNR and DNI order (yes vs. no), the occurrence of shocks (yes vs. no), and the year of death (divided in periods 2007–2009, 2010–2012, and 2013–2016). A *p*-value of <0.05 was used to indicate statistical significance. Analyses were performed using SPSS version 24.

Results

Demographics

Of the 380 patients examined in this study, 333 (88%) were male. Of patients, 110 had their first ICD implanted before 2005 (24 (22%) for primary prevention), 137 patients between 2005 and 2010 (95 (69%) for primary prevention), and 133 patients after 2010 (99 (74%) for primary prevention). There was an increase in ICDs being implanted for primary prevention (*p* < 0.01). Patients had their first ICD implanted at a median age of 67 (IQR 58–73) years. After 2010, ICDs were implanted more frequently in older patients (median age at implantation 70 years) as compared to before 2010 (median age at implantation 65 years) (*p* < 0.01). Also, more ICDs were implanted for primary prevention in the general hospital (78%) compared to the university hospital (53%) (*p* < 0.01).

Patients died at a median age of 71 (IQR 63–78), due to nonsudden cardiac causes (*n* = 122, 32%), sudden cardiac causes (*n* = 47, 12%), or noncardiac causes (*n* = 121, 32%) (Table 1). For 90 (24%) patients, cause of death was unknown. A total of 183 (48%) patients died in the hospital, 85 (22%) at home, and 30 (8%) in a facility (including nursing home and inpatient hospice).

Decision-making about ICD deactivation

Discussions on ICD deactivation. In 81 (21%) medical records, discussions between a professional caregiver and the patient on ICD deactivation were reported (Table 2). Sixty (16%) patients had one discussion with a professional caregiver, and 21 (6%) patients had more than one discussion (range 2–7). Twenty (5%) patients had the discussion as part of a “pre-implantation conversation” with an ICD nurse, all of which were held in the university hospital. For 13 of these patients, this was the only occurrence that a discussion on ICD deactivation was reported in the medical record. Sixty-eight (18%) patients had a discussion after ICD implantation, for 47 patients this was the only time deactivation was discussed. Seven (2%) patients had discussions both before and after implantation. A total of 37 (10%) discussions were held on the day of deactivation. For 25 (7%) patients, this was the only time deactivation was discussed. Fifteen (19%) patients who had a discussion about ICD deactivation, did not have their ICD deactivated. In patients who died in 2007–2009, discussions on ICD deactivation were reported in six (6%) medical records, compared to 13 (12%) for 2010–2012 and 62 (35%) for 2013–2016 (*p* < 0.01).

Characteristics of ICD deactivation. In 112 (30%) medical records, it was reported that the ICD was deactivated before death (Table 3). Sixty-six (59%) of these patients had a previous discussion about deactivation. ICD deactivation was performed through reprogramming the device for 70 (63%) patients, through placing a magnet for 15 (13%) patients, and four (4%) devices were completely removed due to infections. For 23 (21%) patients, it was unknown how the ICD was deactivated. The ICD was mostly deactivated in the hospital in 92 (82%) patients. Four patients had their ICD deactivated at home, three in a nursing home, one in an ambulance and one in a revalidation center. ICDs were mostly deactivated by ICD technicians (69 patients, 62%) and cardiologists (10 patients, 9%). Deactivation was more rarely conducted by emergency physicians (*n* = 2), internists (*n* = 1), anesthesiologists (*n* = 1), oncologist (*n* = 1), and ambulance staff (*n* = 1). The patients’ median age at deactivation was 72 (IQR 65–78) years. Patients died a median of 3 (IQR 0–18) days after deactivation. In 15 (16%) patients who died in 2007–2009 the ICD was deactivated, as compared to 24 (22%) deactivations in patients who died in 2010–2012 and 73 (42%) who died in 2013–2016 (*p* < 0.01).

Care and shocks in the last month of life

DNR and DNI orders and palliative care teams. In 120 (32%) medical records a DNR order was documented (Table 4); this concerned 9 (9%) patients who died in 2007–2009, 30 (28%) patients who died between 2010–2012, and 81

Table 1. Characteristics of ICD patients.

	2007–2009 (n = 96)	2010–2012 (n = 108)	2013–2016 (n = 176)	All (n = 380)	p-value ^a
Gender, male	89 (93%)	90 (83%)	154 (88%)	333 (88%)	0.13
Age at ICD implantation, median (IQR)	67 (58–73)	65 (57–72)	68 (59–74)	67 (58–73)	0.14
Implantation for primary prevention	38 (40%)	57 (53%)	123 (70%)	218 (57%)	<0.01
Type of ICD at first implant					0.35 ^b
Single chamber	31 (32%)	30 (28%)	41 (23%)	102 (27%)	
Dual chamber	37 (39%)	39 (36%)	61 (35%)	137 (36%)	
CRT-D	28 (29%)	36 (33%)	69 (39%)	133 (35%)	
Subcutaneous ICD	0	1 (1%)	4 (2%)	5 (1%)	
Unknown	0	2 (2%)	1 (1%)	3 (1%)	
Type of ICD at death					0.26 ^b
Single chamber	27 (28%)	31 (29%)	35 (20%)	93 (25%)	
Dual chamber	37 (39%)	32 (30%)	54 (31%)	123 (32%)	
CRT-D	31 (32%)	41 (38%)	81 (46%)	153 (40%)	
Subcutaneous ICD	0	1 (1%)	4 (2%)	5 (1%)	
ICD extracted	1 (1%)	1 (1%)	2 (1%)	4 (1%)	
Unknown	0	2 (2%)	0	2 (1%)	
NYHA					0.53 ^b
Class I	6 (6%)	8 (7%)	21 (12%)	35 (9%)	
Class II	59 (61%)	62 (57%)	88 (50%)	209 (55%)	
Class III	27 (28%)	32 (30%)	44 (25%)	103 (27%)	
Class IV	0	1 (1%)	1 (1%)	2 (1%)	
Unknown	4 (4%)	5 (5%)	22 (13%)	31 (8%)	
Comorbidities					
Myocardial infarction	65 (68%)	72 (67%)	105 (60%)	242 (64%)	0.31
Diabetes Mellitus	21 (22%)	28 (26%)	61 (35%)	110 (29%)	0.06
Chronic kidney disease	39 (41%)	48 (44%)	79 (45%)	166 (44%)	0.78
LVEF (≤ 30)	54 (56%)	57 (53%)	94 (53%)	205 (53%)	0.64
Age at death, median (IQR)	70 (62–76)	70 (61–78)	72 (64–79)	71 (63–78)	0.19
Classification of death					0.82 ^b
Nonsudden cardiac	28 (29%)	30 (28%)	64 (36%)	122 (32%)	
Sudden cardiac	11 (12%)	15 (14%)	21 (12%)	47 (12%)	
Noncardiac	24 (25%)	34 (32%)	63 (36%)	121 (32%)	
Unknown	33 (34%)	29 (27%)	28 (16%)	90 (24%)	
Place of death					0.47 ^b
Home	16 (17%)	22 (20%)	47 (27%)	85 (22%)	
Hospital	44 (46%)	54 (50%)	85 (48%)	183 (48%)	
Nursing home	2 (2%)	9 (8%)	15 (9%)	26 (7%)	
Hospice care	0	1 (1%)	3 (2%)	4 (1%)	
Other ^c	2 (2%)	3 (3%)	2 (1%)	7 (2%)	
Unknown	32 (33%)	19 (18%)	24 (14%)	75 (20%)	

Note: Percentages may not add up to 100% due to rounding.

IQR: interquartile range; LVEF: left ventricular ejection fraction; NYHA: New York Heart Association; CRT-D: cardiac resynchronization therapy – defibrillator; S-ICD: subcutaneous ICD.

^ap-values calculated with Pearson Chi-square test.

^bThe “unknown” category was not used in calculating the statistical significance of differences between groups.

^cOther places of death were in the ambulance on the way to hospital (n = 2), in a rehabilitation center (n = 2), outside (n = 2), and in a care hotel (n = 1).

(46%) patients who died in 2013–2016 ($p < 0.01$). In 78 (21%) medical records a DNI order was documented; this concerned five (5%) patients who died in 2007–2009, 25 (23%) patients who died in 2010–2012, and 48 (27%) patients who died in 2013–2016 ($p < 0.01$). Palliative care

team consultations were documented in 17 (5%) medical records, all consultations occurred after 2010. Teams were consulted about medication management or the possible use of palliative sedation. In one case the team was consulted because of a euthanasia request.

Table 2. Characteristics of ICD deactivation discussions.

	2007–2009 (n = 96)	2010–2012 (n = 108)	2013–2016 (n = 176)	All deaths (n = 380)	p-value ^a
Discussions about ICD deactivation	6 (6%)	13 (12%)	62 (35%) ^b	81 (21%)	<0.01
Before ICD implantation	0	0	20 (11%)	20 (5%)	<0.01
After ICD implantation	6 (6%)	13 (12%)	49 (28%)	68 (18%)	<0.01
Number of days between discussion and ICD deactivation (median, IQR) ^c	0 (0-1)	0 (0-3)	0 (0-1)	0 (0-1)	0.78 ^d
Number of days between discussion and death, median, (IQR) ^c	6 (3–32)	5 (1–72)	9 (2–66)	8 (2–55)	0.80 ^d

Note: IQR: interquartile range.

^ap-values calculated with Pearson Chi-square test.

^bSome patients had discussions both before and after ICD implantation.

^cOnly patients with discussions after ICD implantation (n = 68) were included in calculating medians.

^dDifference between medians calculated with Kruskal–Wallis test.

Table 3. Characteristics of ICD deactivation.

	2007–2009 (n = 96)	2010–2012 (n = 108)	2013–2016 (n = 176)	All years (n = 380)	p-value ^a
Total number of deactivations	15 (16%)	24 (22%)	73 (42%)	112 (30%)	<0.01
Type of deactivation					0.39 ^b
Reprogramming	11 (73%)	13 (54%)	46 (63%)	70 (63%)	
Magnet	0	5 (21%)	10 (14%)	15 (13%)	
Extraction	1 (7%)	1 (4%)	2 (3%)	4 (4%)	
Unknown	3 (20%)	5 (21%)	15 (21%)	23 (21%)	
Location of deactivation					0.75 ^b
Hospital	12 (80%)	17 (71%)	63 (86%)	92 (82%)	
Home	0	0	4 (5%)	4 (4%)	
Nursing home	0	1 (4%)	2 (3%)	3 (3%)	
Other ^c	0	0	2 (3%)	2 (2%)	
Unknown	3 (20%)	6 (25%)	2 (3%)	11 (10%)	
ICD deactivated by					0.80 ^b
Cardiologist	1 (7%)	3 (13%)	6 (8%)	10 (9%)	
ICD technician	7 (47%)	12 (50%)	50 (68%)	69 (62%)	
Other ^d	0	1 (4%)	5 (7%)	6 (5%)	
Unknown	7 (47%)	8 (33%)	12 (16%)	27 (24%)	
Age at deactivation, median (IQR)	62 (57–71)	75 (68–80)	73 (66–78)	72 (65–78)	0.02 ^e
Number of days from deactivation to death, median (IQR)	3 (0–23)	2 (0–24)	4 (1–17)	3 (0–18)	0.89 ^e

Note: Percentages may not add up to 100% due to rounding.

IQR: interquartile range.

^ap-values calculated with Pearson Chi-square test.

^bThe “unknown” category was not used in calculating the statistical significance of differences between groups.

^cOther locations of deactivation were: in the ambulance on the way to the hospital (n = 1), in a revalidation center (n = 1).

^dOther persons who deactivated the ICD were: physician other than cardiologist (n = 5), ambulance staff member (n = 1).

^eDifference between medians calculated with Kruskal–Wallis test.

Occurrence of shocks. A total of 268 (71%) patients died with an active ICD. In 114 (43%) of these medical records, one or more shocks were reported (Table 4). Of the patients who experienced one or more shocks, 89% experienced an appropriate shock, and 24% an inappropriate shock. In 20 (7%) medical records, shocks were reported in the last month of life (90% appropriate and 15% inappropriate) and in 5 (2%) on the last day of life (100% appropriate and in 20% inappropriate). Occurrence of shocks in the last

month and on the last day of life did not significantly differ in patients dying in 2007–2009, 2010–2012, or 2013–2016. Of the patients who died with an active ICD, 71 (26%) deaths were classified as nonsudden cardiac, 39 (15%) as sudden cardiac, and 76 (28%) as noncardiac. For 82 (31%) patients, cause of death was unknown. In patients whose deaths were classified as sudden cardiac, shocks in the last month of life were significantly more often reported (28% shocks) as compared to patients whose deaths were

Table 4. Presence of DNR and DNI orders, palliative team consultations, and shock incidence.

	2007–2009 (n = 96)	2010–2012 (n = 108)	2013–2016 (n = 176)	All deaths (n = 380)	p-value ^a
Presence of DNR order	9 (9%)	30 (28%)	81 (46%)	120 (32%)	<0.01
Presence of DNI order	5 (5%)	25 (23%)	48 (27%)	78 (21%)	<0.01
Consultation with palliative care team	0	2 (2%)	15 (9%)	17 (5%)	<0.01
Shocks 30 days before death ^b	5 (6%)	6 (7%)	9 (9%)	20 (7%)	0.80
Shocks 24 h before death ^b	0	2 (2%)	3 (3%)	5 (2%)	0.32
All shocks ^b	45 (56%)	31 (37%)	38 (37%)	114 (43%)	0.02

Note: DNR: do-not-resuscitate; DNI: do-not-intubate.

^ap-values calculated with Pearson Chi-square test.

^bOnly patients with an active ICD at time of dying were included in these calculations: in 2007–2009, n = 81; in 2010–2012, n = 84; in 2013–2016, n = 103.

described as nonsudden cardiac (4% shocks), noncardiac (3% shocks) or unknown (5% shocks) ($p < 0.01$).

Predictors of ICD deactivation. A total of 14 factors were examined to determine their relationship with ICD deactivation (Table 5). Significant predictors of ICD deactivation were the occurrence of ICD deactivation discussions after implantation (odds ratio (OR) 69.30, confidence interval (CI) 26.45–181.59), the presence of a DNR (OR 6.83, CI 4.19–11.12) or DNI order (OR 6.41, CI 3.75–10.96), the occurrence of a palliative care team consultation (OR 8.67, CI 2.76–27.21), and year of death (OR 2.05, CI 1.51–2.78).

Discussion

Decision-making about ICD deactivation

In this study, discussions about ICD deactivation between professional caregivers and the patient were reported in 21% of the patients. Most of these patients had only one discussion reported in their record, occurring after implantation of the device. There was however a steep increase in discussions over the years, from 6% for patients dying in 2007–2009 up to 35% for patients dying in 2013–2016. Discussing ICD deactivation was significantly associated with ICD deactivation, which was reported in 30% of the medical records overall, also with an increase over the studied years from 16% up to 42%. The increase in deactivation discussions and actual deactivation might be attributable to the increased attention to ICD management in the last phase of life, such as the development of expert consensus statements,^{1,4–6} and more general to an increased attention to advance care planning.¹³ The percentages of deactivation discussion and deactivation are in line with a retrospective study conducted in the UK in patients ($n = 44$) who died in 2012 and 2013, showing that 39% of patients had documentation of a discussion about ICD deactivation after implantation.¹² A recent prospective American study in which 51 ICD patients were prospectively followed showed that 26% of the patients discussed the possibility of deactivation with their cardiologist.¹⁴ Two Swedish studies

published in 2014 and 2015 showed that 30–49% of patients had their ICD deactivated.^{3,15}

Despite an increase in ICD deactivation discussions and actual deactivations, current rates are still rather low. Several factors may explain this. It might be possible that actual deactivation discussions were not reported in the hospital medical records,¹⁶ or that these discussions were described in another medical file by another professional caregiver (such as the general practitioner). It is however of utmost importance that conversations about this topic are reported in the medical record, so that other professional caregivers are aware of the knowledge level and preferences of the patient. Secondly, while studies show that many professional caregivers think that the possibility of future deactivation should be discussed in an early stage of the disease,¹⁷ other studies report on barriers on actually engaging in such discussions.¹⁷ Professional caregivers are often unsure about the right time to discuss deactivation,¹⁸ sometimes feel like they do not have a sufficiently well-established relationship with the patient,¹⁹ have too little time to accurately discuss deactivation,¹⁸ find it difficult to predict the end of life,²⁰ or feel that talking about deactivation might be inappropriate, since the ICD was implanted to “safe lives.”¹⁹ Also, a recent international survey study from the UK, conducted in 262 professional caregivers, shows that professional caregivers who are physicians or American, and had initiated a deactivation discussion before, were more likely to discuss ICD deactivation.²¹ This study also identifies that, even though only 30% of nurses were involved in ICD deactivation discussion, 81% of professional caregivers felt that nurses do have the necessary skills to start these conversations, and might therefore play a bigger role in informing patients about ICD deactivation. Further, the study identified that nurses were in favor of informing the patients about ICD deactivation before implantation, which is in line with current guidelines, which advise to discuss ICD deactivation early in the disease process, preferably before implantation, to make the patients aware of the consequences of having an active ICD at the end of life.^{1,4,6}

Although the patient’s willingness to discuss ICD deactivation varies, previous studies showed that patients are sometimes hesitant to discuss ICD deactivation, or might

Table 5. Clinical and nonclinical predictors of ICD deactivation.^a

Predictor variables	OR	95% CI	p-value
Age	1	0.98–1.02	0.94
Gender	0.70	0.37–1.34	0.28
NYHA	1.05	0.72–1.54	0.79
Myocardial infarction	0.98	0.62–1.55	0.94
Diabetes mellitus	0.92	0.56–1.50	0.72
Chronic kidney disease	1	0.64–1.57	0.99
LVEF (≤ 30)	1.33	0.85–2.08	0.21
Indication (primary prevention)	1.38	0.88–2.18	0.16
ICD discussions			<0.01
Before implantation	1.65	0.44–6.23	0.46
After implantation	69.3	26.45–181.59	<0.01
DNR order	6.83	4.19–11.12	<0.01
DNI order	6.41	3.75–10.96	<0.01
Palliative care team consultation	8.67	2.76–27.21	<0.01
Shocks	0.81	0.52–1.28	0.36
Year of death	2.05	1.51–2.78	<0.01

^aUnivariable logistic regression analyses.

OR: odds ratio; 95% CI: 95% confidence interval; NYHA: New York Heart Association; LVEF: left ventricular ejection fraction; DNR: do-not-resuscitate; DNI: do-not-intubate.

even be unaware about the option of deactivation at all.²² Some patients may misunderstand the role and function of the ICD,¹⁷ the distinction between the bradycardia- and tachycardia therapy, and are not always sure why the ICD might intervene.²³ Patients sometimes consider deactivation to be similar to the active ending of life.²³ The active ending of life, or euthanasia, is however defined as medication administered by a physician, with the explicit intention of hastening death at the explicit request of the patient. Euthanasia is legal in the Netherlands, under strict criteria stipulated by the Dutch euthanasia law, and only allowed for patients who are suffering unbearably with no prospect on relief.²⁴ Deactivating the ICD is fundamentally different from euthanasia, since no medication is administered to hasten death. Also, deactivating the ICD will not cause imminent death, contrary to what patients sometimes believe.²⁵ It is important to inform patients about ICD deactivation adjusted to their willingness to engage in these conversations, their knowledge level, and stage of disease.¹³

Care and shocks in the last month of life

In our study, DNR orders were present in 32% of medical records of deceased ICD patients, which is a significant increase since 2007, in which only 9% of patients had a DNR order. Discussing a DNR order has been suggested to be a good opportunity to also discuss possible ICD deactivation.^{1,4,6} Nevertheless, while in our study DNR orders were associated with ICD deactivation, almost half of the patients with a DNR order had an active ICD at time of death. A full advance care planning process including discussions between patients with an ICD, their next

of kin and professional caregivers has been suggested to be a more effective than merely the completion of a DNR order.^{13,26}

Palliative care teams were rarely consulted (5%), possibly because professional caregivers are unsure about the possible contribution of these teams to patient care.²⁷ We did however see that palliative care team consultations were associated with ICD deactivation. There is an unmet need for palliative care in patients with heart failure.²⁸ Not all cardiologists consider end-of-life care to be part of their responsibility.²⁹ Yet, palliative care teams can help to clarify goals of care of ICD patients, and might contribute to patient-centered end-of-life care.³⁰

In patients in whom the ICD was not deactivated, shocks in the last month of life were reported in 20 (7%) patients and shocks in the last 24 h were reported in five (2%) patients. Previous studies showed a higher incidence of shocks, namely up to 32% in the last month of life and up to 68% in the last 24 h of life.² This might be due to different factors, such as the high proportion of patients who have their ICD implanted for primary prevention in our study, which is the main indication for ICD implantation since 2006.³¹ Previous studies that reported on shock incidence are generally older and have high proportions of secondary prevention patients.^{3,15} Furthermore, developments in optimizing ICD programming have resulted in reducing the number of inappropriate shocks at the end of life.^{7,8}

Strengths and limitations

To our knowledge, this is the first study that examines the trends in time of ICD deactivation discussions, ICD

deactivation and ICD shocks and that identifies factors which possibly predict ICD deactivation. Also, this is the largest study to examine shocks in the last month of life. This study does however have some limitations. This study was a retrospective study which relied on the medical records of patients. These medical records could be incomplete,¹⁶ which could have led to underreporting of discussions regarding ICD deactivation. In addition, we did not have insight in the exact content of the deactivation discussions.

Recommendations and future research

Guidelines recommend that discussions on ICD deactivation occur early and on set times during the disease trajectory.^{1,4-6} Educating patients about the consequences of an active ICD in the last phase of life is an important task for the health care professional and has been proven to increase device deactivation.^{23,32} These discussions should include an extensive exploration of the patient's personal values and future goals of care, and should frequently be reassessed, since patients might be subject to changing preferences.¹³ Professional caregivers might be supported in conducting these conversations by palliative care teams, and practical decision aids, such as checklists.³⁰ Documentation of these discussions is crucial, and decisions should be communicated with all involved professional caregivers to avoid misunderstanding and enable good decision-making.⁵ Future research might focus on barriers and facilitators of professional caregivers and patients to discuss ICD deactivation.

Conclusions

The occurrence of ICD deactivation discussions, both before and after implantation, the number of ICD deactivations, the presence of DNR and DNI orders, and the number of palliative care team consultations have increased since 2007. However, ICDs still remain active in the majority of patients at the end of life, who as a result may experience shocks. This study underlines the importance of timely discussions between professional caregivers and patients.

Implications for practice

- Deactivation discussions are significantly associated with implantable cardioverter defibrillator deactivation.
- The implantable cardioverter defibrillator is active at time of death in the majority of patients.
- Seven percent of patients experience shocks in the last month of life.
- Professional caregivers should be educated in performing deactivation discussions.

Declaration of conflicting interests

The authors declare that there are no conflicts of interest

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