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Deactivation of implantable defibrillators at end of life — Can we do better?☆

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ABSTRACT

Introduction: Dying patients with implantable defibrillators (ICD) have a risk of receiving unnecessary shocks before death. The aim of this study was to investigate if deactivation of shock therapy at end-of-life has increased since publication of new guidelines in 2010 on ICD management.

Method and results: This is a study of two groups of ICD patients who died in hospitals before and after publication of new guidelines. Group 1 consists of 89 patients who died between 2003 and 2010. Group 2 consists of 252 patients, the total number of ICD patients in Sweden who died in hospital during 2014. Data was obtained from the Swedish ICD and Pacemaker Registry, Swedish Tax Agency and patient medical notes. Two-thirds died in wards other than Cardiology. Fifty-four percent in group 1 had a Do-Not-Resuscitate-order (DNR) compared to 73% in group 2. Shock deactivation was present in 52% in group 1 and 67% in group 2. The difference in shock deactivation between group 1 and 2 was only significant ($p = 0.014$) for DNR-patients treated in Cardiology. A significant difference ($p = 0.036$) was found in deactivation within group 2 between DNR-patients in Cardiology vs. DNR-patients in Non-Cardiology wards.

Conclusion: Two-thirds of ICD patients die in wards other than Cardiology. Since publication of guidelines on ICD management there is a general increase in shock deactivation for DNR-patients, but only significant for patients in Cardiology. This implicate that actions have to be taken for patients treated in Non-Cardiology wards to bridge the gap between guidelines recommendations and clinical practice.

1. Introduction

Patients with implantable cardioverter defibrillator (ICD) are increasing worldwide. ICD therapy is generally well-accepted by patients, and most patients tolerate ICD shocks because of the lifesaving protection. Appropriate shock therapy has an annual rate of 6.0–7.5% [1,2]. The incidence of inappropriate shock varies between 7 and 24% [1,3–6]. Recently, studies published after the new consensus statements have shown a decrease in inappropriate shocks with a more conservative programming (i.e. higher therapy zones with longer detection intervals and more ATP therapy), further contributing to minimizing the risk of inappropriate shocks in the future [7,8].

However, shock treatment is painful and can cause anxiety, more than a fifth of patients dread shocks [9–11].

Considering deactivation of ICD therapy should take place when prolonging life is no longer the goal of care. Deactivation of ICD therapy is both ethical and legal. No differences exist between refusing initiation of ICD therapy and requesting its withdrawal [12–15].

Deactivation of ICD therapy is both ethical and legal. No differences exist between refusing initiation of ICD therapy and requesting its withdrawal. Discussion about deactivation should be taken into consideration when patient's health is deteriorating and prolonging of life no longer is the goal of care [12–15].

Earlier studies have shown that up to 35% of dying ICD patients are at risk of ventricular arrhythmia, with arrhythmic storm during the last 24 h of life in almost one-fourth of patients. Many patients die with shock therapy still active, with 19–31% of those patients receiving unnecessary shock therapy before death [16–19]. Consensus statements have been published in 2010 to address and highlight the management surrounding these patients nearing end of life [13,15]. The aim of this study was to investigate if deactivation of shock therapy in ICD patients at end of life has increased since publication of new guidelines on ICD management.

2. Method

This is a descriptive study from two groups of ICD patients who died in Swedish hospitals before and after the implementation of new guidelines on the management of ICD patients in end of life.

☆ The authors take responsibility for all aspects of the reliability and freedom from bias of the data presented and their discussed interpretation.

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Data from the Swedish ICD and Pacemaker Registry contributed with data. The registry contains information from all implanting hospitals in Sweden and covers >95% of all device procedures [20,21]. Death certificates, which state both time and location of death, were obtained from the Swedish Tax Agency. Study agreements were obtained from all participating hospitals.

Medical records from the final 24 h were obtained for all patients. The study population's demographic data and data regarding deactivation were obtained from patients' medical records. Last available echocardiograms were collected and the classification for the ejection fraction (EF) described by Lang et al. was used (normal, ≥55%; mildly reduced, 45% to 54%; moderately reduced, 30% to 44%; and severely reduced, <30%) [22].

The first group consists of 89 patients and was taken from an earlier study population of 125 deceased ICD patients, all who died between 2003 and 2010 [17]. All 125 ICD devices were collected from pathology departments. Out of the 125 patients, 89 died in hospital and were included in this subsequent study, referred to hereafter as group 1. During 2014, there were a total of 463 ICD patients who died in Sweden. Of those, 252 died in hospitals and were included in group 2. Patients who had their ICD explanted or had a DNR and deactivation >1 month prior to death were excluded as well as and patients who died in nursing home, hospice or at home (Fig. 1).

Guidelines on the management of ICD patients in end of life were published in 2010 [13,15]. Group 1 consists of patients who died before publications of those guidelines and group 2 consists of patients who died 3 years after publications.

The need for gathering ICD devices for group 2 was considered low. A review of the medical notes from an earlier study [17] showed that notes about deactivation of ICD therapy matched with 100% accuracy to actual device deactivation. All ICD that had been deactivated also had a notation of this in the medical notes. Patients' involvement in the DNR process in this study is not known. Physicians sometimes make decisions regarding DNR and deactivation without involvement of patients depending on the patients' health status.

2.1. Location and death classification

Location of death, including identification of ward specialty, was stated on the death certificates. Type of hospital — university or non-university — as well as ward specialty — in which the patients died were identified. Definition used for "university hospital" was as follows: affiliation with a university that provided clinical education of medical students in addition to delivering patient care. Type of ward specialty was categorized as either Cardiology (including Cardiac Intensive Care Unit and Thoracic Intensive Care Unit) or Non-Cardiology (including Medicine, Intensive Care Unit Acute and Emergency Department and Geriatrics). A decision was made not to split into sub-groups for each specialty due to the low number of subjects in each group.

Death was classified by a modified version of the classification scheme of Epstein et al. [23]. Primary causes of death were divided into two categories: cardiac and non-cardiac death. Comparison between subgroups for specific cause of death was not considered meaningful while the number of individuals was too few. Two investigators performed the classification. They reviewed all deaths, both from medical notes and death certificates. In cases in which investigators disagreed a third investigator reviewed the deaths and a consensus was reached. In group 1 system related (procedure, pulse generator or lead related) death was based on interrogation of patients' ICD devices and medical notes. In group 2 it was based solely on documentation in the medical notes.

2.2. Statistical analyses

Continuous variables were presented as mean and standard deviations or as median and interquartile range whereas categorical variables were presented as percentages. For between group comparisons we used Pearson chi-square, Mann-Whitney *U* test, Inference of proportions or Fisher exact tests. The binomial distribution was used.

The results of a pilot study performed in 2015 at one institution showed that 65% of hospitalized ICD patients with a Do-Not-Resuscitate order (DNR) had therapy deactivated before death. This was a 30% improvement in deactivation compared to our earlier study. To be able to detect a 30% difference from 50% with the margin of error as 10%, and the confidence interval as 95%, a sample size of 43 patients was required to attain an 80% power for the study. Statistical significance was set at two-sided p less than or equal to 0.05. Statistical analysis was performed with SPSS software version 22 and 24.

2.3. Ethics

The study was approved by the Regional Ethics Committee (2008/1527-31/4 and 2014/1787-32/4).

3. Results

3.1. Study group

No significant difference was found between groups regarding age or gender distribution. Co-morbidities between the groups were similar, with the only significant difference found for hypertension ($p = 0.019$), which was more frequent in group 2. The primary prophylactic indication for ICD treatment significantly ($p < 0.001$) differed between groups. The distribution of manufacturers represented in the study was similar to that for implanted devices in Sweden during the same time [24]. The baseline characteristics are presented in Table 1.

3.2. Location and cause of death

Patients in group 1 died in 26 different hospitals, 10 of which (38%) were university hospitals. For group 2, university hospitals represented 11 (17%) out of 63 total hospitals. There was a similar distribution of wards in both groups: 37% versus 31% treated in Cardiology and 63% versus 69% in Non-Cardiology wards (Table 3).

Cardiac death was the most common cause and heart failure the specific cause of death with no significant difference between groups. More system related (procedure, pulse generator or lead related) deaths were found in group 1 than in group 2. Technical malfunction in group 2 is

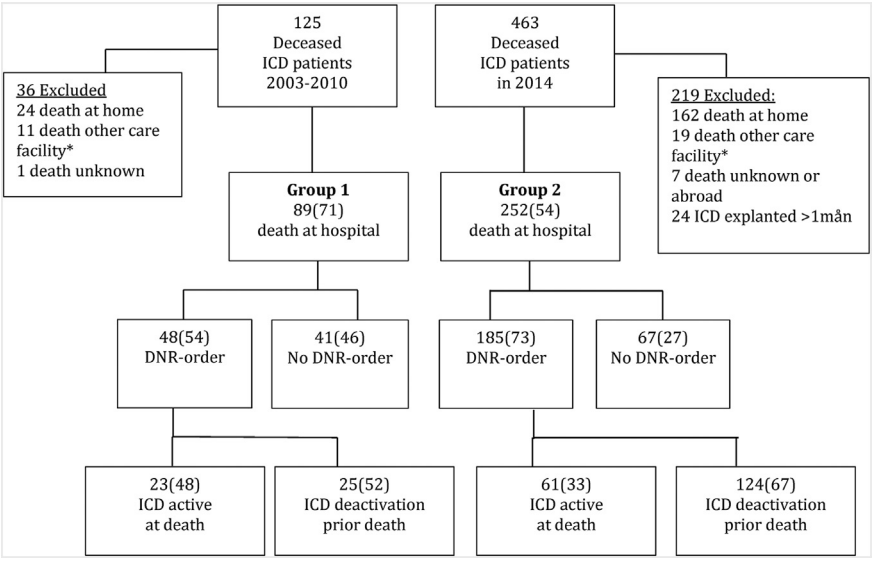

Fig. 1. Inclusion, exclusion criteria. Values are listed as values *n* (%). DNR = Do-Not-Resuscitate. ICD = Implantable defibrillator. *Other care facility meaning hospice or nursing home.

Table 1
Baseline characteristics.

	Group 1 $n = 89$	Group 2 $n = 252$	p-Value
Male	77 (87)	206 (82)	N.S.
Age at death (years)	73.8 ± 8.8	72.8 ± 8.7	N.S.
Duration ICD treatment (years)	3.4 (IQR 1.6–6.1)	4.1 (IQR 1.8–6.3)	N.S.
Morbidity[a]			
Hypertension	21 (24)	94 (37)	0.019
Ischemic heart disease	67 (75)	187 (76)	N.S.
Acute myocardial infarction	60 (67)	144 (57)	N.S.
Heart failure	83 (93)	229 (91)	N.S.
Diabetes mellitus	29 (33)	96 (38)	N.S.
Chronic pulmonary disease	22 (25)	49 (19)	N.S.
Chronic kidney disease	36 (40)	117 (46)	N.S.
Malignancy	16 (18)	54 (21)	N.S.
Stroke	8 (9)	41 (16)	N.S.
Ejection fraction			N.S.
EF ≥ 55%	5 (6)	13 (5)	
EF 45–54%	5 (6)	11 (4)	
EF 30–44%	26 (29)	75 (30)	
EF < 30%	51 (57)	147 (58)	
Unknown	2 (2)	6 (2)	
ICD indication			
Primary prevention	15 (17)	114 (45)	<0.001
CRT-D	30 (37)	110 (44)	N.S.

Values are listed as values *n* (%).
[a] Based on international classification of diseases in the medical notes. Not cause of death.

based on medical notes and not actual device interrogation as in group 1 (Table 2).

3.3. Deactivation

Over half (54%) of the patients in group 1 had a DNR order, when faced with serious illness and imminent death, and 25 (52%) of them had shock therapy deactivated. In group 2 there were 185 (73%) of patients with a DNR order, and shock therapy was deactivated in 124 (67%). The difference in deactivation for patients with DNR was not significant between groups ($p = 0.055$) but did increase significantly 66% ($p = 0.014$) comparing Cardiology wards over time between group 1 and group 2 (Table 3). A significant difference ($p = 0.036$) in deactivation rate for DNR patients was also found within group 2 between patients treated in Cardiology vs. Non-Cardiology. No such difference was found within group 1.

The duration from the decision of DNR to deactivation of shock therapy had a median duration for group 1 of 0.5 (IQR 0–5.25) days and for group 2 it was 1 (IQR 0–4.0) day. Deactivation was performed after 2 days or more for around 40% of the patients in both groups (Fig. 2).

Table 2
ICD therapy deactivation and DNR and different locations.

	Group 1 $n = 89$	Group 2 $n = 252$	p-Value
DNR	48 (54)	185 (73)	0.009
DNR & ICD deactivation	25 (52)	124 (67)	N.S. (0.055)
Cardiology[a]	**33 (37)**	**78 (31)**	**N.S. (0.289)**
DNR	17 (52)	55 (71)	N.S. (0.119)
DNR & deactivation	8 (47)	43 (78)[b]	0.014
Non-cardiology	**56 (63)**	**174 (69)**	**N.S. (0.289)**
DNR	31 (55)	130 (75)	0.041
DNR & deactivation	17 (55)	82 (63)[b]	N.S. 0.397

Values are listed as values *n* (%).
[a] Including Cardiac Intensive Care Unit and Thoracic Intensive Care Unit.
[b] Differences in deactivation within group 2 between cardiology vs. non-cardiology was significant ($p = 0.036$).

Table 3
Mechanisms of death.

Cause of death	Group 1 $n = 89$	Group 2 $n = 252$	p-Value
I Primary organ cause			
A Cardiac	51 (57)	143 (57)	N.S.
1 Arrhythmia	8 (9)	42 (17)	
2 Heart failure	35 (39)	96 (38)	
3 Ischemic heart disease	3 (3)	4 (2)	
4 Other cardiac	5 (6)	1 (0.4)	
B Non-cardiac	38 (43)	109 (43)	N.S.
1 Stroke/cerebrovascular	6 (7)	10 (4)	
2 Other vascular[a]	5 (6)	0	
3 Malignancy	11 (12)	21 (8)	
4 Infection	12 (14)	62 (25)	
5 Chronic obstructive pulmonary disease	3 (3)	3 (1)	
6 Haemorrhage	0	1 (0.4)	
7 Other non-cardiac[b]	1 (1)	12 (5)	
C Unknown	0	0	
II Temporal cause			N.S.
A Sudden ≤1 h	18 (20)	60 (24)	
B Non-sudden >1 h	69 (78)	192 (76)	
C Unknown	2 (2)	0	
III Documentation			
A Witnessed			N.S.
1 Yes	62 (70)	176 (70)	
2 No	11 (12)	39 (15)	
3 Unknown	16 (18)	37 (15)	
IV System related	4 (4)	1 (0.4)	
A Generator	3 (3)[c]	0	
B Lead	1 (1)[d]	0	
C Procedure (per/post op)	0	1 (0.4)	

Values are listed as values *n* (%).
[a] i.e. embolism, aneurysm.
[b] Including renal failure, liver failure.
[c] Undersense of ventricular tachyarrhythmia causing death.
[d] His-ablated patient with exit block.

3.4. Deactivated ICD but no DNR

Five patients in group 1 and six in group 2 had deactivated ICD, but no DNR order. In group 1, one patient died in surgery and four out of five died without any notification of CPR, in these patients death might have been expected despite absence of DNR. In group 2, two patients died during surgery, one with a VT not possible to convert and three patients died during ECMO treatment, in which deactivation is common prior start.

4. Discussion

Majority of ICD patients die in wards other than Cardiology. Since publication of guidelines on ICD management there is a general increase in shock deactivation for DNR-patients, but not for patients treated in Non-Cardiology wards. Awareness about guidelines and the quality of management for terminal ill ICD patients are not high enough and actions have to be taken to bridge the gap between guidelines recommendations and clinical practice outside the cardiology department.

4.1. Study group

Study groups were similar in baseline characteristics, except for differences in hypertension and the indication for ICD. Patients in group 1 received their ICD based on secondary prevention in 83% compared to 55% of cases in group 2. This probably is a reflection of that primary prevention with ICD treatment has become more common, in accordance to guidelines, over time. At the time when patients in group 1 received their first ICD, secondary prevention was the most prevailing indication for ICD treatment in Europe [3,25,26]. Today the indication has shifted and primary prevention is now the leading indication for ICD treatment [21,27,28].

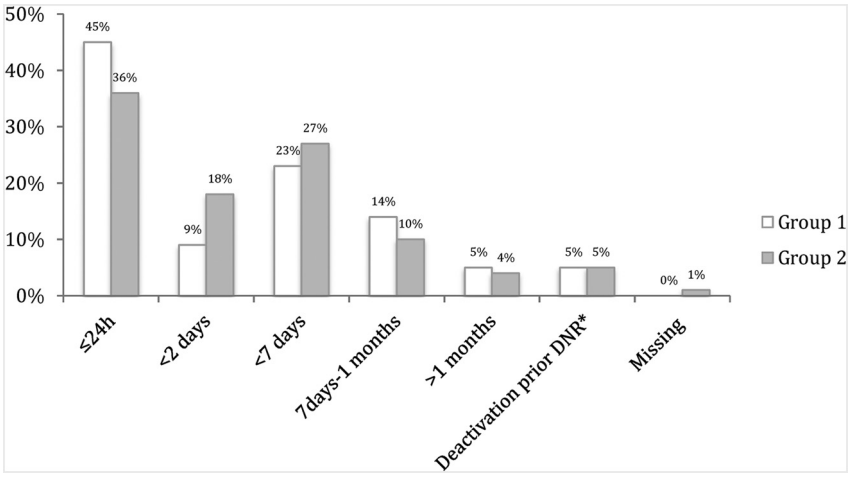

Fig. 2. Duration from decision of Do-Not-Resuscitate order to deactivation of shock therapy in group 1 ($n = 25$) and in group 2 ($n = 124$). *Due to dementia and unknown reasons.

The only difference between groups in respect to co-morbidities was found in hypertension, possibly explained by the higher number of primary preventive patients.

4.2. Location of death

More patients died in university hospitals in group 1 than in group 2. The reason for this can be explained by a higher share of participating university hospitals versus non-university hospitals in group 1, but also that over time more ICD patients are treated outside the university hospital as the treatment is spread. In group 2 all hospitals in Sweden where ICD patients died participated. Furthermore, and as expected, patients are treated in all types of wards throughout the hospital, most often in Non-Cardiology wards. These results are in agreement with the literature. Physicians have to be prepared to meet ICD patients in all types of wards [29].

4.3. Cause of death

Cardiac death and heart failure are the most common cause of death in this population, with similar numbers in both groups, confirming results from other ICD studies [30,31]. The highest number of non-cardiac deaths was infection. A majority of patients in both groups suffered from heart failure, where infection is a common cause of non-cardiovascular deaths [32,33].

4.4. Deactivation

The number of deactivations did increase, although not significantly among DNR patients between the two groups. However for patients with a DNR order treated in Cardiology, deactivation rates have increased with 66%. Furthermore, in group 2 we found that DNR patients treated in Cardiology have their shock therapy deactivated at a significantly higher rate than patients treated in other specialties. This was not the case for patients in group 1, who all died in 2010 or earlier. These results imply that international guidelines possibly helped in the management of patients in Cardiology but not for other specialties. Furthermore during the last 5–10 years, the subject of deactivation has been highlighted more frequently. This could have contributed to a higher awareness among physicians in Cardiology departments. Studies have also shown that awareness of ICD guidelines is low for physicians other than cardiologists [34–37].

A few patients still experience a discrepancy in time between a DNR order and deactivation of therapy. One has to acknowledge the difficulties sometimes associated with deactivation, both for the patients as well as for the physicians. For 10–14% of the patients, the duration was more than a week. This delay exposed patients to an unnecessary risk of shock therapy and should be as short as possible.

Furthermore, sometimes there was a decision not to perform cardiopulmonary resuscitation (CPR) and external defibrillation, but still pursue internal defibrillation with an active ICD. A reason for these types of decisions could be the reduced time for the ICD defibrillation vs. external defibrillation and therefore a higher potential success to convert the arrhythmia.

A risk of developing ventricular arrhythmias in the dying process due to worsening health conditions is not uncommon; deactivation of shock therapy in ICD patients is considered to be appropriate when death is near [13,15]. Allowing therapy to remain active increases the risk of unnecessary shock without any clinical benefit. However, deactivation may not be desirable: according to the principle of autonomy, all patients with ability to do so have the right to make their own health related decisions.

Physicians think deactivation of ICD in terminally ill patients is reasonable, but they rarely discuss it routinely [16,38–41]. These conversations are complicated but should be done early, systematically and continuously over the course of a patient's illness to assist the patient in making an informed choice [13,15,42]. Furthermore, patients' knowledge about ICD treatment and its implications is low and some patients are unwilling to engage in end of life discussions, contributing to the complexity of these conversations [43–46].

The exact number of patients who died with active therapy and had a prior conversation about deactivation is not known. For group 2, it was clearly stated for 3 patients in the medical notes that they wished to have the ICD active no matter what. Patients who have had end of life conversations have proven to have less aggressive medical interventions, less admissions to Intensive Care Unit and fewer incidences of undergoing CPR [47].

ICD patient are treated in all types of specialties. The general knowledge regarding ICD treatment and patient management is not sufficient. Knowledge gaps are identified and acknowledge by the physicians. It exists in all fields but most prominent in the field of geriatrics. With an increasing population with ICD treatment, identification and responsibility for an increase in knowledge has to be identified within each specialty [48].

Have we reached a sufficient number of shock deactivations for patients at end of life? The goal of higher deactivation rates to reduce the risk for unnecessary shocks without any clinical benefit, especially for patients treated in specialties outside Cardiology, must be pursued.

4.5. Limitations

Patients who died in nursing home, hospice or at home were not included in this study due to the absence of medical notes.

This is a comparison between two groups whose collection procedure slightly differed. Both groups are comprised of observational data and difficulties exist in getting comparable data. However, group 2 consists of the whole Swedish population of deceased ICD patients who died in hospital in one year with no random variations. The groups share similarities in many variables therefore making comparisons possible.

Our data might not be representative for other countries or health care systems and due to its descriptive nature, generalizations may not apply to all ICD patients.

Furthermore, patients in group 1 died during a longer time-period (2003−2010) than patients in group 2 who died within the same year (2014). There were differences in indications for ICD implantation due to the clinical shift from secondary to primary prevention. There were few other differences in basic characteristics between groups, so the groups were therefore considered to be comparable.

Classification of death in the absence of results from autopsies is difficult and often subjective. Determining the exact onset of symptoms is difficult especially when patients have chronic symptoms. Many patients had both cardiac and renal failure. There were some patients in whom it was difficult to determine whether pulmonary edema was cardiac or renal in nature.

5. Conclusion

Although there were a general increase in shock deactivation in ICD patients with DNR order since publication of guidelines on ICD management, this was significant only for patients in Cardiology. This implicate that actions has to be taken for patients treated in Non-Cardiology wards to bridge the gap between guidelines recommendations and clinical practice.

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Disclosures

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