



Short communication

## Deactivation of implantable defibrillators at the end of life - A register-based study of ICD-deactivation at home and the impact of palliative care<sup>☆</sup>

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## ABSTRACT

**Background:** The Implantable Cardioverter-Defibrillator (ICD) is a well-established life-saving therapy for heart failure patients, but due to the risk for unnecessary shocks, deactivation of ICD:s is recommended at the end of life.

We aimed to identify i) how many people with HF and an ICD who died in Sweden in 2018 received Specialized Palliative Care (SPC), ii) of those dying outside of hospital, the proportion with deactivated ICDs prior to death for the group as a whole and by SPC access.

**Methods and results:** We analyzed data from i) the Swedish ICD and Pacemaker Registry to find all who died with an ICD in Sweden in 2018, ii) the Swedish Register of Palliative Care and, iii) the Swedish Causes of Death Certificate Register to find those who died outside of hospital. Clinical records were obtained to assess if ICDs were deactivated before death. Descriptive statistics, *t*-tests and chi-squared tests were applied.

46/406 (11%) of those who died with an ICD in Sweden in 2018 had SPC access, of whom 50% also had cancer. 86/164 (52%) ICDs were deactivated prior to death in people dying outside of hospital; higher in those accessing SPC (36/46, (78%) SPC access versus 151/360, (42%) no SPC access;  $p < 0.05$ ).

**Conclusions:** Half of those with HF and an ICD dying outside of hospital had ICD deactivation prior to death. Those accessing SPC were more likely to have their ICD deactivated but few received SPC, without a comorbid cancer diagnosis.

### 1. Introduction

People with heart failure (HF) have a similar palliative care burden in advanced disease compared to cancer patients [1,2] with many experiencing severe symptoms [3]. In a cohort study, 25% of hospitalized HF patients were eligible for specialized palliative care (SPC) – defined as severe/persistent symptoms - but much fewer received this care [4]. A study from the Swedish Register of Palliative Care found that only 4.2% of people dying with HF had accessed SPC [5].

The Implantable Cardioverter-Defibrillator (ICD), used to prevent sudden cardiac death, is a well-established therapy for HF patients. ICD discharge can be lifesaving but painful. Almost a third of people dying from HF with an ICD receive inappropriate and futile shocks in the last 24 h of life [6]. Deactivation of ICDs prior to the dying phase is therefore

recommended [7,8]. The rate of deactivation in people dying in hospitals is between 52 and 67%, with higher rates of deactivation in Cardiology wards [9]. The rate of deactivation of patients dying outside of hospital, at home, in care homes or in palliative care, is unknown.

### 2. Methods

This study is a retrospective, register-based study analyzing data from three Swedish national registers. The study was approved by the Swedish Ethics Review Authority (DNR 2019–06037).

Registers accessed were:

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1. The Swedish ICD and Pacemaker Registry (SIPR) is a national quality register. All cardiac device clinics in Sweden report to the registry and it covers almost all (>95%) of patients with ICD:s in Sweden.
2. The Swedish Register of Palliative Care (SRPC) is a nationwide quality register which aims to include data on all deaths in Sweden. In 2018, it had data for 61% of all deaths, and >95% of patients seen by SPC services.
3. The Swedish Causes of Death Certificate Register (SCDCR) of the Swedish National Board of Health and Welfare covers all deaths in Sweden and includes data concerning cause of death and place of death.

Eligible subjects were any person with an ICD who died during 2018, identified from the SIPR.

### 2.1. Access to specialized palliative care

Access to SPC was defined as being in full time palliative care, delivered by a specialized palliative care centre, at home or in an in-patient unit. In the SIPR we could find names and ID-numbers of patients who died with an ICD in 2018. These data were then linked with the SRPC. For those on both registers, we were able to extract data concerning access to specialist palliative care.

### 2.2. The proportion with deactivated ICDs in those dying outside of hospital

First, we established place of death for all subjects to find those that died outside of hospital. For people who were not in the SRPC, an application was sent to the National Swedish Board of Health and Welfare for permission to extract data regarding place of death from the SCDCR.

The next step was to obtain the ICD deactivation status prior to death.

From the cohort subjects' addresses, we could find out which hospital's heart failure clinic at which they received clinical care. We then wrote to each HF clinic to request copies of clinical records to examine if documented deactivations of ICDs had taken place prior to death.

### 2.3. Analysis

Descriptive statistics present the cohort characteristics. Comparisons of means were made with Student's *t*-test. Comparisons of proportions of those with and without deactivated ICDs, and access or no access to SPC were made with chi-square-test.

## 3. Results

In 2018, 406 people (83% men; mean age at death 73.3 [range 16.6 to 91.8]) found in the ICD-register had died with HF and had an ICD. They had lived with their ICD for a mean time of 3.8 years (range 6 days to 13.7 years) (Table 1).

Just over half (225, 55%) were also registered in the SPCR. Compared with those not in the SPCR, these patients were significantly older (74.8 vs 71.5,  $p < 0.05$ ) but the sex distribution was similar ( $p = 0.33$ ).

### 3.1. HF-patients receiving SPC

Out of the 406 patients with HF and ICD, 46 (11,3%) received SPC either at home ( $n = 18$ ) or in a SPC-unit ( $n = 28$ ). 23/46 (50%) of the patients that received SPC also had a cancer-diagnosis. Thus, only 23/406 (5,6%) of patients received SPC due to HF alone.

**Table 1**

Group characteristics of 406 patients who died in Sweden with an ICD in 2018.

	All $n =$ 406	All DOH $n =$ 172	SPC $n =$ 46	no SPC $n =$ 126	
Age at death	73.3	74,4	74,1	74,6	Years
Age at implant	69.5	70,3	69,8	70,5	Years
Time with ICD	3.8 335	4,1	4,3 35	4,1	Years
Men	(82.5)	143 (83.1)	(76.1)	108 (85.7)	n (%)
Women	71 (17.5) 341	29 (16.9)	(23.9) 40	18 (14.3)	n (%)
PPICD	(84.0)	148 (86.0)	(87.0)	108 (85.7)	n (%)
SPICD	65 (16.0)	24 (14.0)	6 (13.0) 35	18 (14.3)	n (%)
ICD Deactivated	N/A	86 (52.4)	(77.8)	51 (42.9)	n (%)
ICD not Deactivated	N/A	78 (47.6)	(22.2)	68 (57.1)	n (%)

DOH = Died out of hospital, SPC = Died out of hospital and in Specialized Palliative Care, PPICD = Primary Prophylactic ICD, SPICD = Secondary Prophylactic ICD.

### 3.2. Place of death

All patients in the SRPC had a recorded place of death and 112 of these died outside of hospital. Of those not in the SRPC, an application was sent to the National Swedish Board of Health and Welfare to extract data regarding place of death from the SCDCR.

where we found an additional 60 patients who died outside of hospital, making a total of 172 patients. Of those dying outside of hospital, 86 (50%) died at home, 58 (34%) in a care home and 28 (16%) in an SPC in-patient unit.

Data regarding place of death were missing from the SCDCR in 13 patients.

### 3.3. ICD-deactivation

Extracts from clinical records regarding deactivation were successfully retrieved in 164/172 (95%) of patients who died outside hospital. Of these 86 (52%) were deactivated, less than previously reported for patients dying in hospital, 67% [6].

## 4. Discussion

Just over half of those dying at home with an ICD, had ICD deactivation prior to death. This may be due to practical difficulties; if patients are too sick to attend the pacemaker clinic for deactivation, technicians – and even magnets – may be less available in the community. Patients receiving SPC were however significantly more likely to having had their ICD deactivated than those who did not (36/46, 78% versus 151/360, 42%;  $p < 0,05$ ) (Fig. 1).

However, only a very small proportion of people dying with HF with an ICD received SPC.

The low levels of access to SPC for people with HF compared with those with cancer is consistent with other published work [5]. Our finding that many people who had access to SPC also had a cancer diagnosis is similar for people dying with other organ failures such as chronic obstructive pulmonary disease (COPD), where only 17% of patients with COPD alone received palliative care support compared with 57% of those with lung cancer [10].

Those dying at home need the same consideration regarding ICD deactivation as those dying in hospital. Referral to SPC often includes advance care planning, and a needs-based referral to SPC for those with complex, severe or persistent problems should overcome the still-present barrier of a prognostic approach. In addition, symptoms and concerns may not reach the threshold for SPC referral, but their ICD still needs deactivation.

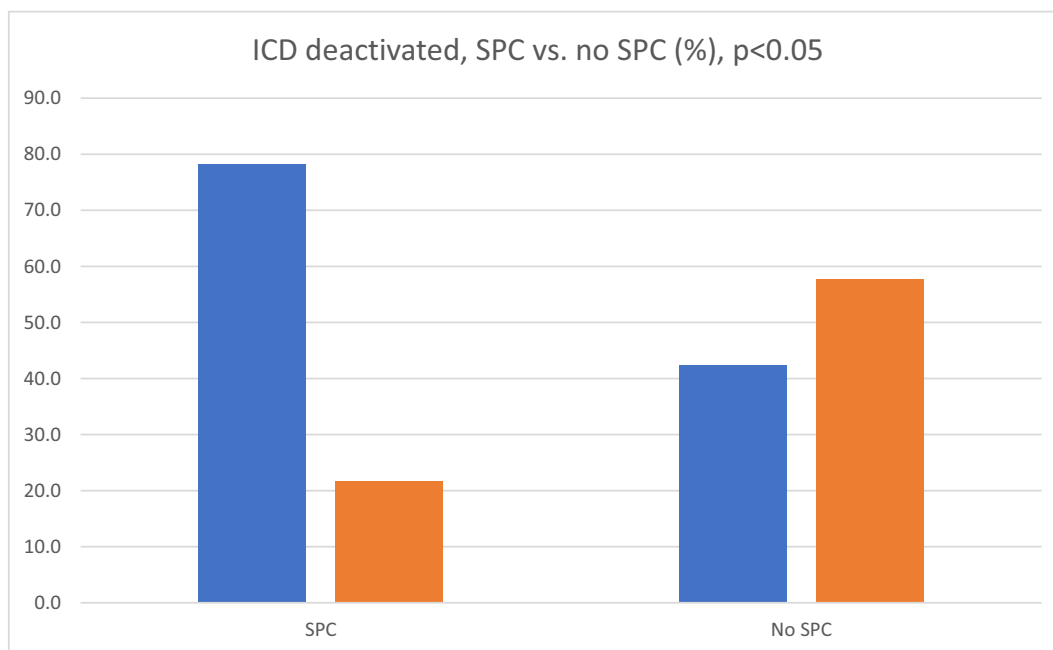


Fig. 1. ICD deactivated (blue), not deactivated (orange) before death in patients dying outside of hospital comparing those receiving SPC vs. not receiving SPC. (SPC = Specialized Palliative Care). (For interpretation of the references to colour in this figure legend, the reader is referred to the web version of this article.)

## 5. Strengths and limitations

The SIPR does not contain data on heart failure status in patients, only the indication for the implant, so some patients may not have had HF. However, 84% of ICDs were primary preventive devices for which the indication is the presence of HF with a reduced ejection fraction. The remaining 16% had their ICD implanted after surviving sudden cardiac arrest of whom, most had ischemic or dilated cardiomyopathy. Seven patients had hypertrophic cardiomyopathy, two had long QT-syndrome, one sarcoidosis and two patients arrhythmogenic right-ventricular cardiomyopathy. Excluding these 12 patients, leaves >97% of patients in the cohort with heart failure at the time of death.

The SRPC captures data from >95% of patients known to SPC services. This means that the number of patients receiving SPC is likely to be accurate, though others in the cohort may have received some form of basic palliative care.

The proportions of men vs. women in the group are uneven but reflects the incidence of heart failure with reduced ejection fraction (HF-rEF) (70% men and 30% women) - the group of HF-patients with an indication for ICD-treatment.

Clinical record entries regarding deactivation were taken as evidence for deactivation, and absence of these were taken to imply that the device was not deactivated at the time of death. Permanently deactivating an ICD requires a programming device, available only at special centers, thus such an intervention would have been documented. However, some patients may have had temporary deactivation using a magnet. Patients are unlikely to have such a magnet at home, but some SPC Home Care services do have access to ICD-magnets. We cannot be certain that some people receiving SPC had an undocumented deactivation, thereby underestimating the benefit associated with SPC service access.

There was a significant proportion of those in SPC with a cancer diagnosis (50%) compared to the overall access to SPC (11%) but to make an exact comparison we would have needed to know how many of all patients in the study who had a cancer diagnosis, but these data were only available for those in SPC.

## 6. Conclusion

Fewer people dying at home from HF and who have an ICD have the device deactivated prior to death compared with those dying in hospital. Access to SPC services greatly increased the number of those with ICD deactivation, but only about one in ten had SPC access. Of those accessing SPC, the referral was likely to be driven by a comorbid cancer diagnosis for many.

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## Declaration of Competing Interest

The authors report no relationships that could be construed as a conflict of interest.

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