



# Defibrillator patients should not be denied a peaceful death



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## ABSTRACT

**Background:** Implantable defibrillators (ICDs) prevent sudden cardiac death. With declining health, ICD therapy may prolong death and expose the patient to unnecessary pain and anxiety. Few studies have addressed end of life care in ICD patients. The objective of this study was to investigate end of life in ICD patients, with respect to location of death; duration between do-not-resuscitate (DNR)-orders and deactivation of ICD therapy or DNR and time of death.

**Methods and results:** A descriptive analysis of 65 deceased ICD patients, all whom had a written DNR-order before death, is presented. The majority (86%) was treated in hospitals, mainly (63%) university hospitals, and many (33%) in cardiology wards. Despite DNR-order, ICD shock therapy was active in 51% of all patients. In those with therapy deactivated at death, therapy deactivation was carried out two days or more after DNR-order in more than a third (38%). The time from DNR decision to death in patients with therapy active had a median of four days (IQR 1–38). During the last 24 h of life, 24% of the patients experienced shock treatment.

**Conclusions:** The majority of ICD patients with a DNR-order were treated in university hospitals. More than half still had shock treatment active at time of death with a median of four days or more between DNR decision and death. Patients with therapy deactivated, two days or more elapsed in more than a third from DNR decision to deactivation of therapy, exposing patients to a high risk of painful shocks before death.

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## 1. Introduction

The implantable cardioverter defibrillator (ICD) is highly effective in saving lives [1–5]. Eventually patients may develop terminal illness and a decision of retaining ICD therapy active or not is paramount.

The exact number of active implants in the world is unknown, but recent surveys showed over 130 000 active implants/year in the USA and 70–80 000 in Europe [6,7]. Faced with this increase in ICD treatment, end of life related question of discontinuation of ICD treatment is inevitable.

When a patient's health status deteriorates, a decision to issue a do-not-resuscitate (DNR)-order can be taken. This does not equal ICD deactivation, but for patients who desire comfort care and consent to deactivation, it is not only appropriate, but also ethical and legal to withdraw defibrillator shock therapy [8,9]. Few studies have addressed patients with ICDs at end of life. One revealed an increased risk of shock therapy in the last week [10]. We have previously shown that despite a DNR-order, almost two thirds of ICD patients still had therapy active and a fifth had shocks before death [11]. However, little is known about

where these patients die, if different specialities handle dying ICD patients differently and if there is enough time to deactivate therapy in this population. How much does ICD competence influence therapy deactivation?

The aim of this study was to investigate end of life in ICD patients, with respect to location of death; duration between DNR-order and therapy deactivation; or DNR and time of death.

## 2. Patients and methods

### 2.1. Study group and device collection

This is a descriptive analysis of 65 deceased ICD patients all of whom had a written DNR-order before death (Fig. 1). The study population was also included in an earlier study [11].

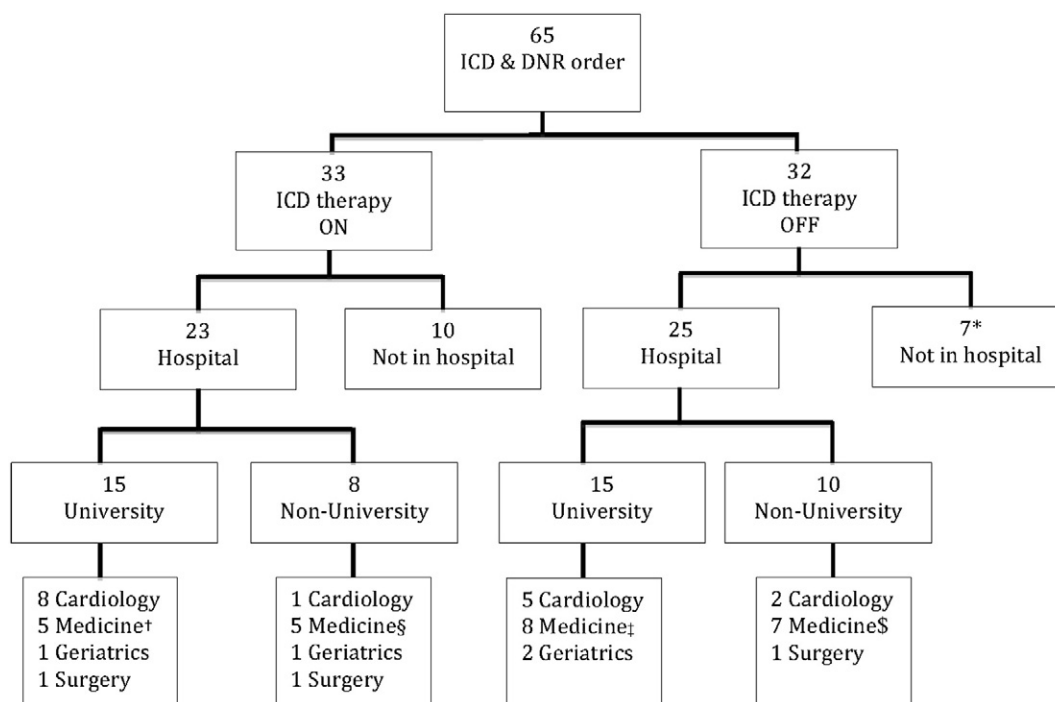
This is a nationwide study with 26 participating hospitals, which prospectively enrolled 130 ICD devices from deceased patients. In Sweden it is mandatory to explant devices (pacemaker or ICD) after death. The pathology departments of all participating centres were asked and agreed to take part in the present study before device enrolment. All ICDs were sent to the study centre. Of 130 patients, all those (65) with a written DNR-order or in palliative care were included and analysed in this study.

The study population's demographic data were obtained from patients' medical records, the Swedish ICD and Pacemaker Register, and

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**Fig. 1.** Study flowchart (n = 65). ICD = implantable defibrillator. \*One patient's location of death is missing. †Medicine ward including oncology (1). §Medicine ward including infection (1), intensive care unit (2). ‡Medicine ward including intensive care unit (1). \$Medicine ward including oncology (1).

the National Board of Health and Welfare. Death certificates were obtained from the Swedish Tax Agency.

## 2.2. Time and location of death

Location of death, type of hospital, university or non-university, as well as ward specialty, where the patient was receiving care when death occurred, were identified. The definition of a university hospital was an affiliation with a university and provision of clinical education of medical students, in addition to delivering patient care.

Type of specialty was categorized as cardiology, medicine (including infection, oncology and intensive care unit), geriatrics, hospice (including nursing home) and home.

The time of death for patients dying in a hospital was established from medical and nursing notes and from death certificates, which stated the time, cause, and location of death. For patients dying at home, the time of death was assessed from the death certificate and, if available, notes from the palliative care team. If death was witnessed, the time of death was accepted as correct.

## 2.3. Do-not-resuscitate

The time from a decision to issue a DNR-order and therapy deactivation as well as time to death were analysed.

## 2.4. Deactivation

Therapy deactivation can be performed either permanently by programming the ICD shock therapy off or temporarily by placing a specific magnet over the device. As long as the magnet remains in place, therapies are off. Date of deactivation was collected from the medical notes and in some devices the date and time of deactivation, also with magnet placement, was available at post-mortem interrogation.

## 2.5. Active therapy

All the ICDs were interrogated and data regarding deactivation, incidence of shock treatment for 24 h prior to death were retrieved.

## 2.6. Shock treatment

The incidence and number of shocks delivered were recorded. Shock treatment within 24 h of death was classified as shock at end of life. In addition to the occurrence of any shocks, we assessed the number of shocks received during the last 24 h of life.

## 2.7. Death classification

Death was classified using a modified version of the classification scheme of Epstein et al. [12]. Two investigators reviewed all deaths. The primary causes were divided into cardiac and non-cardiac deaths.

## 2.8. Statistical analysis

Data was summarized with descriptive statistics. Continuous variables were presented as mean and standard deviations or as median and interquartile range whereas categorical variables were presented as percentages or as confidence intervals of proportions [13]. The normal approximation to the binomial distribution was used. This is valid because if  $np = 10$  and  $n(1 - p) = 10$ , then  $p$  can be assumed to have an approximately normal distribution, where  $n$  is the sample size and  $p$  is the proportion [14]. Statistical analysis was performed using SPSS software version 22.

## 2.9. Ethics

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

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