

# Ethical Dilemmas and End-of-Life Choices for Patients with Implantable Cardiac Devices: Decisions Regarding Discontinuation of Therapy

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## Opinion statement

It is our belief that a well-designed cardiac device management program should include end-of-life patient and family planning, addressing potential decisions regarding withdrawal of pacemaker and/or implantable cardioverter defibrillator therapy. Guided by the basic ethical and legal principles outlined in the article, it is the responsibility of the electrophysiologist and other involved health care providers to introduce this topic to patients, provide guidance and resources for decision making, and honor both patient and family requests.

## Introduction

Recently, the Heart Rhythm Society (HRS) addressed management of implantable cardiac devices (specifically pacemakers and implantable cardioverter defibrillators) in patients and their families who wish to withdraw from therapy, especially in the context of end-of-life decision making [1••]. The 2010 HRS Consensus Statement attempts to pro-

vide cardiac electrophysiologists and other health care providers guidelines for decision making regarding this sensitive subject. Just as evidenced-based consensus guides decisions regarding insertion of these devices, this article lends support for the decision to end these treatments. Like other ethical decisions, the purpose of this article is not to change an indi-

vidual's values, instead it intends to introduce the topic, provide rationale for decision making, and to ultimately help providers to examine their own values. These steps may aid both the electrophysiol-

ogist as well as other health care providers in transforming the nature of end-of-life decision making regarding device therapy so as to provide a dignified quality of life, even at the end stage of life.

## Background

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The invention of permanent cardiac pacemakers in the late 1950s and 1960s followed by the development of the implantable cardioverter-defibrillator (ICD) in the early 1980s represented true milestones in the science of cardiovascular medicine. For the first time, lethal periods of bradycardia, and later ventricular tachyarrhythmias, could be effectively managed by means of a surgically implanted device. Death rates due to bradycardia and later from lethal ventricular arrhythmias declined remarkably in patients who received these devices. The more recent development of cardiac resynchronization therapy (CRT) as a treatment for congestive heart failure has further expanded the population that can benefit from implantable cardiac device therapy.

These devices, along with other advances in cardiac care, have allowed many individuals to survive illnesses that previously would have resulted in a rapid physical decline and early death. Although this development was heartily embraced by both physicians and the public alike, it has had the unintended consequence of producing ever-increasing numbers of people who live with chronic, debilitating, and progressive illnesses that will ultimately result in death. In addition, the prevention of death from a cardiovascular cause often allows an individual to live long enough to develop other life-threatening diseases such as cancer. At present, an estimated 1,479,350 individuals will be diagnosed with cancer each year in the United States alone, with more than 562,340 cancer-related death occurring in the United States each year [2]. Thus, the ever-expanding use of implantable cardiac devices in an ever-aging and progressively sicker population will produce a growing number of patients who will reach the end of their lives with an implantable cardiac device in place. For the most part, the ethical dilemmas surrounding cardiac device deactivation were not an issue prior to the development of the ICD, which could cause recurrent unpleasant shocks in patients dying from a terminal illness. Studies have reported that as many as 20% of patients with ICDs in place at end of life receive defibrillation shocks that are both painful and upsetting, decreasing the quality of the final stages of their lives while at the same time causing unnecessary distress among family and caregivers [1••, 3].

The rise of the modern Hospice movement in the United States, with its emphasis on the palliation of a terminally ill patient's symptoms, has helped bring the issue of deactivation of implantable cardiac devices at end of life into greater awareness. With the coming of the 21st century, considerable discussion arose in the medical, legal, and ethical literature regarding issues that arise when these devices are deactivated in terminally ill patients [4-6]. The

ultimate result of these discussions was the development of the HRS Consensus Statement on the management of Cardiovascular Implantable Electronic Devices in patients nearing end of life or requesting withdrawal of therapy. This article attempts to very briefly summarize this and other articles that deal with this challenging topic. The reader interested in more detailed discussions can find them elsewhere (in the references provided).

## Basic ethical and legal principles

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The majority of ethical concerns in medicine can be summarized by four basic principles: 1) respect for patient autonomy, 2) beneficence, 3) non-maleficence, and 4) justice (as stated in the HRS Consensus statement) [1••]. To these, many authorities will also add the concepts of “dignity” and “honesty” [5]. What do these terms refer to? A brief definition follows:

- Respect for Patient Autonomy (*voluntas aegroti suprema lex*)  
This acknowledges the right of an individual to self determination, implicit that an individual has the right to choose or refuse a particular treatment option.
- Beneficence (*salus aegroti suprema lex*)  
This refers to actions that promote the well being of others, and by extension that the medical practitioner should act in the best interest of the patient.
- Non-maleficence (*Primum non nocere*)  
This is implicit in the statement “First do no harm,” that it is more important not to harm the patient than to do them good. The duty is to try to prevent harm from coming to patients.
- Justice (*Justitia*)  
This refers to the duty to treat patients with fairness and equality, in particular in the distribution of limited resources.

Although not included in the HRS document is would seem appropriate to add the following two additional principles:

- Dignity  
Although difficult to define, it refers to the innate right of the patient to respect and esteem, as well as the implicit right to ethical treatment.
- Honesty  
That an individual should be fully informed and comprehend the possible benefits as well as risks of any potential treatment option.

Using these principles (as well as other legal precedents), we can derive the following principles:

- 1) That a patient has the legal and moral right to refuse (or have withdrawn) any medical treatment or intervention.
- 2) That when a person is not capable of decision making, their legally defined representative has these same rights.

- 3) Legally, all adults are presumed competent and capable of understanding the implications of their decisions. An individual's competence (or lack thereof) is a condition that can only be determined by the courts.

## Management of cardiovascular implantable electronic devices in patients nearing end of life or requesting withdrawal of therapy

### Withdrawal of device therapy versus euthanasia

- Many physicians are reluctant to withdraw cardiac device therapy due to a concern that this represents a form of physician-assisted suicide or euthanasia [7••]. There are two points that can refute this concern: 1) the intent of the practitioner, and 2) the actual cause of the patients' death. In discontinuing an undesired treatment the intent is not to harm the patient, rather it is to remove an unwanted intervention that the individual perceives as an interference. In the case of physician-assisted suicide, the patient acts to end his own life using methods or materials provided by the physician, whereas in euthanasia the physician knowingly acts to end the patient's life by a direct action. In each of these settings death occurs as a result of the action taken, whereas in the case of withdrawal of therapy death occurs due to the effects of the patients underlying disease [1••].
- The US Supreme Court has held that these decisions are not one regarding the right of an individual to die, rather it is a right of an individual "to refuse unwanted treatments," and that withdrawing or withholding treatments does not constitute physician-assisted death [1••]. They have also stated that the law applies to the person, not to the treatment in question.

### Pacemaker versus ICD discontinuation

- Although many practitioners would agree to the deactivation of an ICD when the patient has reached the end of life, many are uncomfortable with the discontinuation of pacemaker therapy (especially when the patient is dependent on the device for survival.) To address this, the HRS statement draws distinctions between both constitutive versus regulative therapies as well as replacement versus substitutive therapies [1••]. Regulative therapies are those that restore the body's own normal equilibrium, whereas constitutive therapies take over a function that the patient's body can no longer provide for itself. The latter can be further subdivided into two categories: 1) treatments that "substitute" for a lost function (such as hemodialysis) that the body can no longer perform, and 2) those that "replace" a lost function (such as a renal transplant) and thereby

become a part of the patient. The decision to stop a pacemaker does not introduce a new set of medical problems to the patient (just as stopping hemodialysis would be far different than the invasive effects of removing a transplanted kidney). Thus a pacemaker is an artificial therapy that an individual could ask to be discontinued in the same way that the patient can request that mechanical ventilation be discontinued. Despite these arguments, a recent study found that up to one third of medical professionals surveyed felt that stopping pacemaker therapy was comparable to physician-assisted suicide or euthanasia [7••]. Kay and Bittner [8•] have expressed serious concerns about the discontinuation of pacemaker therapy in patients who are dependent on these devices.

### Perspectives in patient care

- In the terminally ill patient, there can come a time when the presence of an implanted cardiac device (that had been appropriately placed years or decades earlier) may become an instrument by which an individual's suffering may be prolonged, resulting in ever-increasing emotional, spiritual, and financial burdens to both the patient and their family. More and more patients and their families report a sense of abandonment by their physicians (and the medical system as a whole) at end of life. How can these potential conflicts be resolved?
- 1) *Integrate end-of-life decisions into the management of patients with implanted cardiac devices.* As noted, the management of a patient with an implantable device should be proactive, in that a decision to turn off the device should be addressed by clinicians with the same planning, care, compassion, and dignity that contributes to the decision to initiate the therapy. Much in the literature has addressed the topic of coping with implantable cardiac defibrillators and impact on quality of life [9, 10]. The recognition by some clinicians that the patients with these life-saving devices (and their families) often experience anxiety, depression, and maladaptive coping skills after implantation has guided interventions so that patients may enjoy an improved quality of life. Yet, the concept of preservation of a quality of life must extend to include the final stages of that life. Hence, end-of-life care should be viewed as a "core competency" for all those who deal with these patients [11]. Addressing this topic may seem premature and may even be uncomfortable for many health care providers, those of whom practice daily to prolong life, but clinicians who respectfully help prepare patients in the final stages of life best serve the overall needs of patients and families. Indeed, as noted, it is the responsibility of the electrophysiologist to respect and address end-of-life decisions regarding device management in all patients.
- 2) *Incorporate a team approach to manage psychological issues of patients with implantable cardiac devices.* Although the health care hierarchy would suggest that discussions concerning end-of-life care for

patients with devices should be the responsibility of the electrophysiologist, this assumption may place patients at risk of not having these issues addressed. Cardiac device nurses are often on “the front line” to initiate conversation with patients and families concerning psychological device issues. Cardiologists, family practice physicians, and nurses all have a responsibility to address both emotional as well as physical concerns. A simple, “how are you coping with your device?” is frequently enough to open the door to honest discussion and build the foundation for a future dialogue about end-of-life care. A team approach will best serve to ease patient and family fears, and convey that assessment of patient psychological well-being is as important as physical well-being. A mental health care provider should ideally be an essential member of the patient care team, assuming that clinicians lay the groundwork for patients with a device to consider discussing end-of-life care [12]. Patient support groups for people with cardiac devices may also facilitate discussion on this topic. Discussing these matters with the patient’s religious and cultural leaders is also critical to effective decision making, as religious and cultural influences are often of great importance at the end of an individual’s life.

- 3) *Education of team members.* Germane to the advanced preparation of both the patient and family in end-of-life decisions regarding implantable cardiac devices is the education of team members involved in the patient’s care. It is known that physicians are somewhat less likely to feel comfortable discussing deactivation of a cardiac pacemaker and ICD compared to other types of life-sustaining therapies such as mechanical ventilation, dialysis, and feeding tubes [13]. Team members should examine their own values regarding the deactivation of cardiac devices (even before an issue arises). Clinician education should stress that the decision to deactivate pacemakers and implantable defibrillators is both an ethical and a legal one.
- 4) *Handling disagreements.* In the case of a disagreement between patient and practitioner, consultation with the ethics department and/or palliative care providers can be of great benefit. However, let us again repeat that the simplest solution to many of these problems is to engage in a thoughtful conversation with both the patient and their family regarding medical device deactivation during advance care planning. Unfortunately, it is in this very arena that modern practitioners seem to be the most uncomfortable and sorely lacking in skill. In general, cardiac electrophysiologists no longer tend to have the close bond they once did with their patients, and this lack of personal connection makes these discussions regarding the end of life particularly difficult. As other health care providers often tend to defer such discussions to the electrophysiologist, the result may be a lack of any substantial discussion regarding the status of cardiac device therapy when the patient reaches the end of life. Indeed, these problems are indicative of modern medicine’s increasing separation of the physician from the patient [14, 15]. Patients are often identified only by the illness from which they suffer,

causing an unfortunate transformation from a unique individual person to a mere “vessel of disease” [16]. It is becoming more and more apparent that physicians (in particular those responsible for the implantation and maintenance of these devices) and their staffs need to engage in discussions with patients and their families regarding management of cardiac device therapy in the setting of a potential future “terminal illness.” As the number of cardiac devices implanted continues to increase, the need for these discussions will be ever greater. We must remember that one of the principle goals of all medical care is to ease human pain and suffering, and that these devices (implanted with the best of intentions) may at some point interfere with one of the very things we would all wish for our families and ourselves, a painless and peaceful passage into the end of life.

## Disclosure

B. Grubb is a consultant for Medtronic and has received honoraria from Biotronik. B. Karabin has received honoraria from Medtronic, and has received payment for development of educational presentations and had travel expenses covered by Medtronic Biotronik.

## References and Recommended Reading

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- Of importance
- Of major importance

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