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Life-Saving Devices Reach the End of Life with Heart Failure

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Abstract

The new millennium has seen a dramatic increase in use of potentially life-prolonging devices such as implantable cardioverter-defibrillators (ICDs) and ventricular assist devices (VADs) among patients with advanced heart failure. Most patients who receive these devices will have them in place when they die. Clinicians who care for these patients must commit through the entire course of therapy, including the end-of-life. Discussions about device deactivation should be the standard of care and this discussion should take place prior to implantation, during annual heart failure reviews, after major milestones, and when the end-of-life appears to be approaching. Turning off ICDs and turning off VADs in response to patient or proxy requests are legally the same although they may be perceived differently, as disconnection of the VAD is more likely to cause immediate death. This article discusses the evidence around device deactivation at the end-of-life and offers suggestions for improvement.

Introduction

Advances in therapy during the past 20 years have dramatically changed the outlook for patients with symptomatic heart failure (HF). Presentation with New York Heart Association Class IV symptoms used to herald death within 2 years, which usually occurred suddenly at home. Now earlier recognition of left ventricular dysfunction and initiation of neurohormonal antagonist therapy has lengthened the period of good quality survival with mild-moderate heart failure. Even after congestive symptoms have occurred, freedom from congestion can often be achieved during hospitalization and maintained at home with integrated heart failure disease management. The first decade of the new millennium has seen the “rise of the machines”¹ which have further improved functional capacity and survival with heart failure. Implantable cardioverter-defibrillators (ICDs) include features such as detection and defibrillation of life-threatening ventricular tachyarrhythmias before they cause sudden cardiac death, and cardiac resynchronization (CRT) with additional leads to improve ventricular function and functional capacity in patients with favorable QRS morphology. Ventricular assist devices (VADs) propel blood from the heart to the central

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Conflicts:

Dr. Matlock – none

Dr. Stevenson - none

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circulation to augment the cardiac output of patients with otherwise terminal circulatory failure. Further, both therapies continue to undergo rapid evolution to include additional functional and monitoring features offering even greater benefits with fewer risks.

However, all technologies that are implanted with the beneficent intent of prolonging life will eventually become unnecessary or unwanted, and can sometimes do harm if they become a device that is prolonging the end-of-life. Clinicians providing ongoing care for patients with advanced cardiac technologies must recognize their responsibility through the entire journey of the patient's illness. This requires familiarity and comfort with discussions about prognosis of HF and competing risks from co-morbidities, and with decisions regarding what-ifs, including device deactivation. While quality patient-centered care mandates that goals and preferences of the patient and family should drive decision making, the onus of initiating these discussions generally falls to the clinician. Discussions about why, when, and how a device would be deactivated should be the standard of care for clinicians who care for patients with advanced heart failure and should not be out-sourced to a hospice or palliative care team.

Epidemiology and Functions of Major Implantable Cardiac Devices

This review will highlight decisions regarding ICDs and VADs, two increasingly common devices representing opposite ends of a spectrum. On one hand, the ICD is a bystander device which in the majority of patients never does anything, and for the rest of patients never does anything most of the time. Its role is to detect and correct potentially life-threatening rhythm disturbances, which it does very effectively unless the rhythm is secondary to an event that is itself fatal, such as a massive myocardial infarction or an aortic dissection. By contrast, VADs are implanted to provide continuous support to maintain cardiac output and circulation for a heart that is too weak to support life on its own.

ICDs

ICDs provide an opportunity to prevent sudden cardiac death. Once reserved for patients who had survived cardiac arrest (secondary prevention), ICDs have been shown in large clinical trials to confer a 23 to 36 percent relative risk reduction (a 5 to 7 percent absolute risk reduction over 3–5 years) in all-cause mortality for a substantial population of HF patients identified on the basis of reduced left ventricular ejection fraction (with or without previous myocardial infarction) as being *at risk* for their first fatal arrhythmia (primary prevention).^{2–4} These trials have led to class 1 guidelines that recommend ICD therapy for all HF patients meeting the criteria of these trials (New York Heart Association Class II or III HF symptoms, ejection fraction less than 35%).⁵ The caveat that patients should have anticipated survival of at least one year with good functional capacity is appropriate and reasonable but difficult to codify.⁵ Based on these data, the Centers for Medicare and Medicaid Services determined that ICDs would be a covered benefit for the nearly 500,000 eligible Medicare beneficiaries.⁶ Currently, physicians in the United States are implanting approximately 10,000 ICDs per month.⁷

The standard ICD can serve several functions. The primary purpose is to detect and treat potentially fatal arrhythmias with an electric shock to restore normal rhythm before sudden cardiac death occurs. They also routinely have anti-tachycardia pacing which attempts to abort a potentially lethal arrhythmia through pacing rather than through a defibrillator shock. Both anti-tachycardia pacing and cardioversion-defibrillation occur more often than they prevent sudden death, as many episodes of ventricular tachycardia terminate spontaneously with return to normal rhythm in patients without ICDs. Only episodes of successfully terminated ventricular fibrillation can be assumed to have been truly aborted sudden death. Current ICDs also serve as a back-up pacemaker in the event that a patient develops

bradycardia either as a primary rhythm or after defibrillation. As episodes of bradycardia occur commonly in both normal patients and patients with heart failure, it is not known how often back-up pacing may be life-saving.

Cardiac resynchronization (CRT)

CRT, also known as bi-ventricular pacing, devices have a pacing lead in each ventricle to synchronize ventricular contraction in patients with marked electrical dys-synchrony. This can be associated with significant improvement in ejection fraction, functional capacity, and quality of life in up to 2/3 of patients with QRS prolongation of over 150 msec in a left bundle branch block pattern.⁸ CRT can be implanted as a stand-alone device that provides pacing but no defibrillation, which has been shown to prolong life as well as improve it. The stand-alone CRT device is the most common CRT device implanted in most European countries. The CRT device can also be combined into one device with the ICD (the CRT-D), which is the most common CRT device implanted in North America. CRT devices thus occupy a unique part of the device spectrum. Unlike the ICD alone (the “bystander device”), they improve cardiac function, patient functional capacity and quality of life in selected patients. CRT devices without defibrillation components do have modest but less demonstrable impact on survival, which may result from the improvement in cardiac function and/or the presence of back-up pacing. It is important to recognize that the defibrillation, resynchronization, and back-up pacing features of the CRT-D can each be activated or deactivated separately, but this will not be discussed further

VADs

Current VADs take blood from the ventricle of the heart and pump it into the aorta to either supplement or provide all of the cardiac output. At about the same time of the first human heart transplant, the VAD program was initiated by the National Institutes of Health with the intention of providing permanent circulatory support.⁹ The technical challenges, including prevention of device thrombosis, were far greater than envisioned. In the mid-80s there was shift to developing VADs as temporary support for patients awaiting heart transplantation, for which the first approval was in 1994.¹ With increasing durability and survival, the direction shifted again to include more permanent support with the REMATCH trial completed in 2001.¹⁰

Technological advances have been rapid in this field. Initially, VADs were pulsatile, with a pumping mechanism that attempted to mimic the pulse pressure of the native heart. While these early devices conferred a 48% relative risk reduction in all cause mortality compared to patients on maximal medical management, survival was still only 23% at two years (compared to 8% in the medical management arm).¹⁰ Contemporary devices are smaller, have fewer moving parts, and pump a continuous flow of blood. A more recent trial comparing continuous flow VADs to pulsatile VADs demonstrated a 58% vs. 24% two-year survival favoring the continuous flow devices.¹¹ Additionally, the continuous flow devices had fewer complications and significant improvements in functional capacity and quality-of-life.¹¹ Estimated 2-year survival is now in the range of 50–60% with continuous flow devices. Even with the newer devices, over half of the patients had suffered a major adverse event at 2 years, including reoperation to replace a malfunctioning or thrombosed pump (10%), disabling stroke (11%), and death (33%).¹¹ Additionally, infection of the device,¹² gastrointestinal bleeding,¹³ and frequent hospitalizations occur often.

Improving outcomes from the Interagency Registry for Mechanically Assisted Circulatory Support (INTERMACS) have heralded dramatic increases in the use of this technology.¹⁴ There has been a steady rise in the number of patients receiving VADs with 273 patients receiving VADs in 2007 and 1740 in 2011.¹⁴ After the approval of continuous flow VADs

for destination therapy (DT) - lifetime therapy without transplantation), the number of patients receiving DT VADs has increased from 37 (3.9% of all VADs) in 2009 to 464 (30.6% of all VADs) in 2010, and in 2012 for the first time have outnumbered VADs as bridging devices until heart transplants. People between the ages of 40 and 59 receive 44% of all VADs implanted, with another 40% in patients between the ages of 60 and 79.¹⁴

Although indications are for either bridge or destination therapy, actual practice includes three major categories of adults receiving implantable VADs for durable ambulatory use: almost one third of recipients are already listed for transplantation and considered true “bridge” recipients; a smaller but increasing proportion are implanted as “destination” (DT) or lifetime therapy in patients considered ineligible for transplantation; and a third heterogeneous group is comprised of about 40% of recipients for whom the device is inserted to allow time to determine whether transplantation is appropriate, bridge to candidacy.” About half of these “Bridge to candidacy” patients will go on to transplantation. For the others, underlying physiological or psychosocial conditions may be found to be contraindications, or complications from the VAD itself (such as infection or stroke) and may lead to ineligibility. The patients who receive VADs anticipating eventual transplantation but never undergo transplantation are sometimes considered to reside in “VAD purgatory”.

Fate of Cardiac Devices Intended to Prolong Life

Current Practice Surrounding ICD Deactivation

ICDs usually stay in for life. Occasionally, an ICD will be surgically removed due to an infection or rarely, significant anxiety.¹⁵ ICD leads may have to be replaced due to fracture from defects or excessive “wear and tear”. The generator is usually replaced for battery depletion approximately every 5 to 7 years, less if chronic pacing is required. Approximately 30% of all current implants are replacements. For the majority, patients with ICDs will have a device in place at the end of their life, necessitating a careful, deliberate, and patient-centered approach on the part of the clinician to handle these devices as death approaches.

The current practice around ICD deactivation is haphazard and inadequate. From the clinician standpoint, there are multiple barriers to confronting the issue of deactivation. Studies have demonstrated that between 20%¹⁶ and 46%¹⁷ of clinicians question the legality of deactivating an ICD. Other more qualitative studies document that many clinicians are uncomfortable with the content of the discussions and would desire more formal training.^{18–20} While most clinicians felt it was important to disable the ICD in terminally ill patients,^{20–24} it remained unclear about who should initiate these discussions²³ and only the minority actually admit to having had these discussions.^{19;22}

From the patient standpoint, many are unaware that the ICD can be deactivated.²⁵ Among a group of family members of deceased patients, only 27% reported actually having had a discussion about ICD deactivation prior to death.²⁶ Consequently, some patients are getting shocked unnecessarily at the end-of-life. Over half of the hospices surveyed in the United States had a patient within the past year receive shocks from their ICD (although this was mitigated if the hospice had an explicit policy surrounding ICD deactivation).²⁷

Importantly, most patients with ICDs are not shocked at the time of expected death, even if the ICD remains active. Most patients with heart failure die of bradyarrhythmias or pulseless rhythms, without ever developing a “shockable” rhythm. Terminal shocks at the end of life are unlikely except in patients who have experienced multiple previous shocks while alive. In one retrospective chart review of 63 patients, only 21% of the patients were actually shocked by their ICD.²⁸ However, there is no reliable way to predict who will die with bradyarrhythmia and who will die with tachyarrhythmia. The process of death is sufficiently

momentous for the patient and surrounding family that extraneous pain and suffering should be avoided for both. Deactivation should be performed when feasible for all patients in whom death is anticipated in the near future, although the exact horizon is uncertain.

Limited Experience around VAD Deactivation

Those VADs that serve only as a bridge to transplant are removed prior to transplantation and then become irrelevant. However, VADs are increasingly being used for permanent therapy either for destination by intent or for the patients in whom the hope of transplantation will never be realized. Indeed, only 42% of devices explicitly for bridging and 6% of devices for “bridge to candidacy” were replaced by heart transplants at the time of the last annual report of INTERMACS.¹⁴ Thus the majority of VADs are for lifetime support; although initially implanted for life prolongation, they will eventually become end-of-life VADs.

Death with VADs has been reported in 868 patients as of June 30th, 2011,¹⁴ in whom the VAD was presumably turned off at some time. However, even less is known about turning off VAD devices than about deactivating ICDs. There is virtually no information about how patients and families with destination therapy approach end-of-life decision making, nor about the site and details of the end. There are several anecdotal reports in the literature about patients who died poorly with their destination VAD but it is difficult to draw conclusions from these.^{29;30} Two single site review articles shed some light onto the end-of-life experiences. One review of 22 patients in Toronto showed that 7 died after the patient or surrogate requested deactivation.³¹ Another review of 68 patients showed 14 deaths.³² In both reviews, the majority of the decisions to deactivate the VAD fell to the families or other surrogate decision makers. While several authors have proposed that there is a need to discuss VAD deactivation^{33;34} it still remains unclear how these conversations have proceeded. Some authors have written about the importance of preparing the patients and caregivers pre-operatively using a “preparedness plan” which could include a discussion about the inevitable deactivation at the end-of-life.³⁵

Preparing Patients with Devices for the End of Life

Before Implantation

Understanding the Disease: The first steps in preparing patients for the end of life with a device should occur prior to initial device implantation. Patients need to understand the disease of heart failure and where they are along the journey. (For the purpose of the rest of this review, mention of the patients is assumed to include the patients’ families as appropriate.) This should include elicitation of the patient’s understanding of their disease, their goals and preferences regarding survival, quality of life, and anticipated wishes in the event of unanticipated adversity. All patients with advanced disease as well as those undergoing major procedures should have identified a health care proxy and reviewed general advanced directives.

Risks and Benefits of the Device: There should be systematic education regarding the purpose and functionality of the device, and the prognosis with and without the device. In the case of ICDs, current evidence suggests that patients are not as informed as they should be with evidence suggesting disempowered patients³⁶ and paternalistic physicians who think their patients’ preferences do not matter.³⁷ Anticipated adverse events and the possibility of rare unexpected events should be reviewed. Information including statistics is difficult for patients to assimilate; use of natural frequencies instead of percentages such as “If we put this in 100 patients like you, we would expect....” may facilitate understanding.³⁸ This has been articulated for explanation of ICD for primary prevention.³⁹ Particularly for ventricular assist devices, further information such as the likelihood of transfer to inpatient

rehabilitation and the impact of the device on the lives of caregivers should also be delineated. The details of how information should be presented prior to consent for major procedures have been reviewed by Krumholz.⁴⁰ Information should always be presented with the recognition that “No” may be the right answer for some patients, provided they have had adequate opportunity to ask questions and share the factors in the decision. Many programs committed to VAD implantation enlist a palliative consult service to help communicate and facilitate discussion around the decision to undergo VAD implantation.

Possibility and Process for Turning Device Off: Prior to device implantation, discussion should include the possibility that a time may come when the device should be turned off. This generally triggers a lengthy discussion regarding different modes of death and the possibility that patients could die from causes other than their heart failure, such as a stroke or cancer. Discussion should also include details of how the device would be turned off, as many patients assume that it would require a surgical procedure. In the case of the ICD, it should be clarified that defibrillation can be deactivated while the resynchronization or other pacing features remain active.

Device Replacement: Patients should also understand the possibility that the device or parts of the device may need to be replaced. In the case of the ICD, this could relate to defective leads or generators, infection, or routine battery end-of-life. Patients receiving the device for primary prevention may have a less favorable balance of risks and benefits for replacement, particularly if the device has never delivered a therapy and heart failure or other co-morbidities present competing risks to sudden death as a mode of exit. VAD replacement for thrombosis, infection, or device breakdown is obviously a more severe level of intervention, not anticipated but also not uncommon. Patients should understand that in the event that any device replacement may be indicated, there will again be discussion regarding the balance of benefits and risks, and the patient could opt to decline replacement, even if advised by the medical team.

After Device Implantation

Regular Review: Once the device is implanted, the patients should have an periodic review of their progression and goals so that they are aware of their disease trajectory and their options.⁴¹ For patients with advanced heart failure, this has been recommended to take place annually on a scheduled basis and at the time of major milestones such as a heart failure hospitalization or ICD shock.⁴¹ Review should, in general, take place more often after VAD, particularly if the outcome has been compromised by adversity such as continued right heart failure, stroke, recurrent GI bleeding, or resistant drive-line infection. During this time, patients can readdress their advance directives as their disease course changes. Reviews should include also questions regarding the “what-if” scenarios most likely to arise.

Device Replacement: As discussed above, the consideration of device replacement should never be taken for granted. It should be accompanied by similar discussion as prior to the original implant as above. The clinical team, patient and family should appreciate that “No” is an acceptable answer if based on adequate comprehension.⁴²

Approaching the End of Life

Initiating the Discussion: A sober and thoughtful approach must be taken to prepare and support patients and families as the end of life approaches. Death is a guaranteed outcome; it is a natural part of life and clinicians who view death as a failure of medical therapies and technology will have difficulty engaging in discussions around future plans in general and device deactivation in particular. There are several challenges that make the timing of deactivation discussions difficult. First, in the non-acute setting, it is extremely difficult to

predict prognosis among patients with heart failure; the best prognostic indices are at least 50% wrong over half the time.⁴¹ Thus, knowing when to bring this discussion up in the non-acute setting is difficult, but can be facilitated by the regular reviews and milestones as above. At other times, the reason for the discussion regarding prognosis is painfully clear, such as after a devastating stroke or during severe sepsis from an infected device. Here, the challenge is less in the timing of the discussion than the emotional temperature, which can run very high. In these settings, decisions often fall to surrogates who may have difficulty with the substituted judgment required of a surrogate decision making.

Clinicians who care for these patients should anticipate the intensity of emotions that may arise. Two recent statements have both addressed suggested communication skills which can be used in the care of patients with advanced illness.^{41:43} While details are beyond the scope of this review, it worth emphasizing that clinicians who care for patients with advanced illness need to develop skill and confidence in responding to emotions. Dealing with emotional responses is an essential prelude to effective communication on the more cognitive level. Simply pausing and acknowledging an emotion can help patients and families know that you are there with them. Simple tools for communicating during difficult situations include phrases such as “I’m worried...” or “I wish”, such as “I’m worried that your spouse won’t wake up again” or “I wish things were different, I know how hard this must be”.

Device Deactivation Decisions: The legal and ethical considerations surrounding deactivation are clear and uniform. While withholding and withdrawing a therapy may feel quite different in practice, ethically and legally, they are not different. Clinicians are ethically bound to discuss this with the patients and families.⁴¹ Recently, an expert consensus statement outlined the ethics and practice of device deactivation.⁴³ If the patient (or surrogate decision maker) requests to have a device turned off, principles of autonomy and self-determination dictate that it should be turned off. Failure to do so is legally “assault”.⁴⁴ On the other hand, many patients become ready for an approach focused more on palliation and quality of life, but retain strong visceral feelings about the support and reassurance they have received from their devices and do not want to turn them off. For some patients, reassurance is needed from religious counsel that turning off a device to allow natural death at the end of life is not suicide.

Because ICDs and VADs represent two ends of the extreme, each therapy also carries its own unique challenges. ICDs have other potential functions that also need to be considered as part of the deactivation discussion such as back up pacing, bi-ventricular pacing, and antitachycardia pacing. It would be quite reasonable for a patient to elect to only turn off the shocking function of the ICD and leave the pacing functions active as these often provide symptomatic benefit. It also might be reasonable for a patient or family to deactivate all of the functions of the device where they have chosen to stop all life support.

VADs are unique in that they are providing a majority of the function for an otherwise failing heart. Deactivation often leads to death in a very short period of time. Because of this rapid decline, disconnecting a VAD may feel different than disconnecting other forms of artificial life support, particularly if the patient is awake and communicating prior to the deactivation. However, patients and surrogates have the right to determine that therapies be withheld or withdrawn, such that disconnecting the VAD can be seen as simply allowing a patient to naturally die of the progression of native heart disease.

The Procedure of Deactivation

ICD: The physician with whom the patient or proxy has made the decision should provide appropriate documentation and timing in the chart. The defibrillation procedure can be

simply performed using the device programmer. This is done in many major hospitals by a member of the electrophysiology team. In other facilities or at home when a member of the electrophysiology team cannot be present, deactivation can be accomplished by a trained representative of the device manufacturer after appropriate documentation. Patients and families often require careful reminder that the patient is unlikely to look any different after the device is turned off, as they may anticipate immediate death.

Some hospices have policies regarding discussing device deactivation with patients, while many do not.⁴⁵ If the patient chooses not to deactivate the defibrillation feature, it is advisable to have a special device magnet at hand. Holding or taping this in place will prevent device shocks without deactivating pacing features.

VAD: In the hospital the VAD can be turned off by a physician, nurse or coordinator familiar with the equipment, taking care to deactivate the alarms that are designed to be insistent. For a patient who is on a ventilator, it is strongly advised to turn off the ventilator at the same time as the VAD, regardless of which has received the primary focus of termination. For a patient at home, it is most appropriate for a member of the VAD team to come to the house. Most hospice team members are not sufficiently experienced to disconnect a VAD although this may change over time. Depending on the state of the native heart and circulation, it may be anticipated that some patients will survive for days supported by the residual function of their own heart. This can be accompanied by many symptoms of terminal circulatory failure, for which the care team should plan effective narcotics and sedatives for pain and anxiety. During a period of survival with the VAD turned off, the risk of major embolic events is high, again with the risk of severe suffering and misery that require vigilant intervention for relief.

Conclusions

Devices such as ICDs and VADs marvelous examples of the way advances in technology can extend life. However, implanting the device is in many ways the simplest part of device therapy. Despite the large gains in outcomes among patients with heart failure, it remains a relentlessly progressive disease for many. Death is still guaranteed, and a clinician measuring success solely by the number of lives saved will fail 100% of the time if they follow their patients long enough. The rise of the machines invests important responsibility in those who activate them. Clinicians caring for patients with advanced cardiac devices must become comfortable discussing device deactivation, not only to preserve the dignity of dying, but also to regain the grace of our predecessors who accompanied their patients through the entire journey to accept death with equanimity.

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Abbreviations

CRT	Cardiac resynchronization therapy
DT	Destination therapy
HF	Heart failure
ICD	Implantable cardioverter-defibrillator
VAD	Ventricular assist device

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Box**Major Points in Care for Patients with Cardiac Devices at the End of Life**

1. The new millennium has seen a dramatic increase in use of potentially life-prolonging devices (ICDs and VADs) among patients with heart failure.
2. Most patients who receive these devices will have them in place when they die.
3. Clinicians who care for patients with advanced cardiac devices should commit to caring for patients through the entire course of therapy, including deactivation of devices to allow natural death.
4. Discussions about device deactivation should be the standard of care.
5. Clinicians should take responsibility for discussing potential deactivation prior to implantation, during annual heart failure reviews, after major milestones, and when the end-of-life appears to be approaching.
6. Device replacement should entail thoughtful review of ongoing indications and likelihood of benefit.
7. Turning off ICDs and turning off VADs in response to patient or proxy request are legally the same although perceived differently, as disconnection of the VAD is more likely to cause immediate death.