

## REVIEWS

# Quality of Death: Implantable Cardioverter Defibrillators and Proactive Care

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**Objectives:** *The purpose of this paper is to discuss quality of death (QOD) among patients with congestive heart failure (CHF) and implantable cardioverter defibrillators. We outline recommendations that enhance QOD from the device patient and specialty cardiology perspectives.*

**Background:** *Contemporary treatment of CHF patients routinely includes both pharmacologic therapy and the use of cardiac devices. The implantable cardioverter defibrillator prevents premature death in heart failure patients, though not death itself.*

**Conclusions:** *Active discussion and consideration of patient's QOD is indicated in implantable cardioverter defibrillator patients to prevent unnecessary treatment and to increase control over perceived quality of life by patients and family. (PACE 2006; 29:637–642)*

**implantable cardioverter defibrillator, palliative care, heart failure, psychosocial, end of life, quality of life**

### Introduction

Congestive heart failure (CHF) is a syndrome characterized by progressive pump failure and recurrence of symptoms that include shortness of breath and effort intolerance. Patients with CHF also have an increased incidence of sudden death although this outcome has been significantly improved by the development and utilization of implantable cardioverter defibrillators (ICDs).<sup>1,2</sup> The comprehensive care needed in the treatment of CHF patients includes both pharmacologic therapy and the use of cardiac devices.<sup>3</sup> Although the ICD was invented to prevent premature death in heart failure patients, it does not prevent death itself. The impact of ICDs in patients without structural heart disease provides a direct benefit in reducing sudden death but the utilization of this device in patients with progressive CHF becomes more complex. The ICD effectively converts an acute life-threatening condition into a chronic disease, producing new challenges in facilitating the best possible end of life (EOL) scenario. Previously, physicians treating CHF had to deal with general resuscitation issues but ICD care prompts advanced care planning discussions including shock-related issues as well.

Quality of death (QOD) refers to the ultimate cessation of life after medical care has been deemed futile, with full engagement of patient and family desires. Many patients and families acknowledge and respect the patient's inevitable death and appropriately seek control over death's impending arrival. The notion of QOD implies a health outcome minimizing pain and suffering, maximizing the autonomy of the patient's wishes, and respecting the sanctity of life. The withdrawal of life-sustaining treatment and the consideration of EOL issues has an extensive literature across a variety of disease states,<sup>4</sup> although this area has not been adequately explored in the context of CHF-ICD patients. The empirical evidence supporting ICD and cardiac resynchronization technology in CHF has prompted a rapid change in care pathways throughout the spectrum of care. For the CHF-ICD patient, the QOD definition requires medical management of symptoms and discomfort, an active discussion of ICD shocks, and full consideration of patient and family desires for care.

The purpose of this paper is to outline the issues surrounding EOL care for CHF-ICD patients, and to provide a framework of management that optimizes patient care and comfort in the face of death. This includes recommendations to enhance QOD from both patient and provider perspectives.

### Quality of Life in ICD Patients

Health-related quality of life (QOL) is broadly defined as the impact of disease and medical treatment on patient overall functioning and well

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Received December 13, 2005; revised February 13, 2006; accepted February 20, 2006.

being. QOL is a construct that includes physical functioning, disease- and treatment-related symptoms, and social functioning.<sup>5</sup> The potential experience of shock uniquely characterizes the ongoing care of CHF-ICD patients from other cardiac and CHF patients.<sup>6</sup> The shock sensation has been likened to a swift kick in the chest and rated as a “6” on a 0 – 10 pain scale.<sup>7,8</sup> Summaries of QOL research indicate that “the ICD is at least equal to, or better than, antiarrhythmic medications on most indicators of QOL.”<sup>9–13</sup> However, large randomized trial data have suggested that ICD shock is associated with QOL reductions.<sup>14</sup> Collectively, QOL and QOD outcomes in CHF-ICD patients may be highly dependent on the minimization of ICD shocks.

### Shock at EOL

Improvement in the care of ICD patients who are dying is both necessary and needed. Recent research examined whether dying ICD patients were approached by their doctors to discuss the option of deactivating their device.<sup>15</sup> Next of kin were questioned as to whether this type of discussion had taken place, with only 27 out of the 100 patient families studied confirming that they had discussed this option. Further, 27 patients received a shock in the month preceding their death, one-third of whom also received a shock within the last minute of life. Only nine of these 27 patients had discussed deactivation beforehand; six ultimately decided to do so. The study is limited in that it was conducted in only one hospital with a relatively small group of patients, but it highlights the need for ICD patients and their doctors to be more active in the advance care planning process during the final months of life, particularly because shocks can continue to occur late into the dying process. Certainly not all shocks can be prevented but the presence of worsening Class IV CHF could be a signal for patient discussion of shock and EOL issues.

### CHF Prognosis and Referral to Hospice

Although CHF is a progressive syndrome, the current care model is predominantly aggressive care or hospice care. The current use of hospice care for cardiac patients is very small; approximately 11% of hospice patients in 2003<sup>16</sup> suffered from end-stage heart disease. There are several rationales for the relatively low referral rate to hospice for CHF patients. First, the definition of “end of life” for entry into hospice is the determination that death will occur within the next 6 months. Due to the frequent episodes of decompensation seen in CHF patients with subsequent recovery, it is difficult for practitioners to estimate EOL in this population. In addition, there may be uncer-

tainty on the part of the physicians as to what type of palliative care is warranted,<sup>17</sup> as well as practical issues, such as insurance coverage and hospice utilization.<sup>18</sup>

The CHF-ICD disease management team is a model where the integration of palliative care and discussion of EOL issues can easily be incorporated into care. EOL care for CHF-ICD patients should involve exploration of all treatment options, including device deactivation. While discussion of device inactivation may not be comfortable, patients should be made aware of the option, thereby increasing their right to make autonomous decisions about their EOL care. Incorporating this into the CHF-ICD management team strategy, and targeting key personnel who have the empathy and skill sets to communicate the options for EOL care, could all help to promote a better QOD for CHF-ICD patients.

### QOD in CHF-ICD Patients

End-stage cardiac disease is a condition in which palliative care is both appropriate and necessary. The education of cardiac patients and their families about palliative care options is essential to understanding EOL issues surrounding cardiac device technology. According to the World Health Organization, palliative care “is an approach that improves the QOL of patients and their families facing the problems, associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.”<sup>19</sup> The American Board of Hospice and Palliative Medicine<sup>20</sup> added that “such relief requires the comprehensive assessment and interdisciplinary team management of the multidimensional needs of patients and their families.” A team approach allows for a broader set of communication styles and expertise with which to optimize physical, psychosocial, and spiritual care. In one study of palliative care, which included CHF patients, at one year patients had significantly less anxiety, dyspnea, improved sleep quality, and improved spiritual well being. This was accompanied by fewer ER visits and visits to primary care physicians, with no significant increases in specialty clinic visits.<sup>21</sup> Formiga and colleagues<sup>22</sup> surveyed 80 end-stage CHF patients as to their thoughts and concerns about EOL care. Forty percent of those surveyed reported not wanting resuscitation measures to be utilized, and nearly 60% did not wish for their course of treatment to focus on allowing them to remain alert until time of death. Although the two biggest areas of concerns for this sample was pain and symptom management and unnecessary prolongation of life,

only two participants had actually discussed such wishes and concerns with their physician.

**Clinical Discussion**

**Post Shock and Deactivation Considerations**

The occurrence of shock in any ICD patient can prompt appropriate and inappropriate thoughts about mortality and possible device deactivation.<sup>6</sup> Device deactivation presents unique challenges to both patients and health-care providers, and is not always an easy decision. Physicians often do not readily address EOL procedures with their patients. This lack of communication plays a role in making the deactivation process more strained. Although formal guidelines do not

exist, we propose recommendations to facilitate discussion and decision-making among patients and providers with the hope that improved communication will increase patient awareness about treatment options, enhance patient autonomy, and demonstrate empathy on the part of the health-care provider. We propose guidelines using a palliative care decision-making tree and the acronyms “C.A.R.E.” and “N.E.E.D.S.” for both providers and patients in an effort to enhance the QOD experience (see Figs. 1 and 2).

Before speaking with a patient about deactivation, keep in mind their capacity to receive and understand information. It may be beneficial to provide written materials, such as handouts. Advance Directives are a necessary component of the

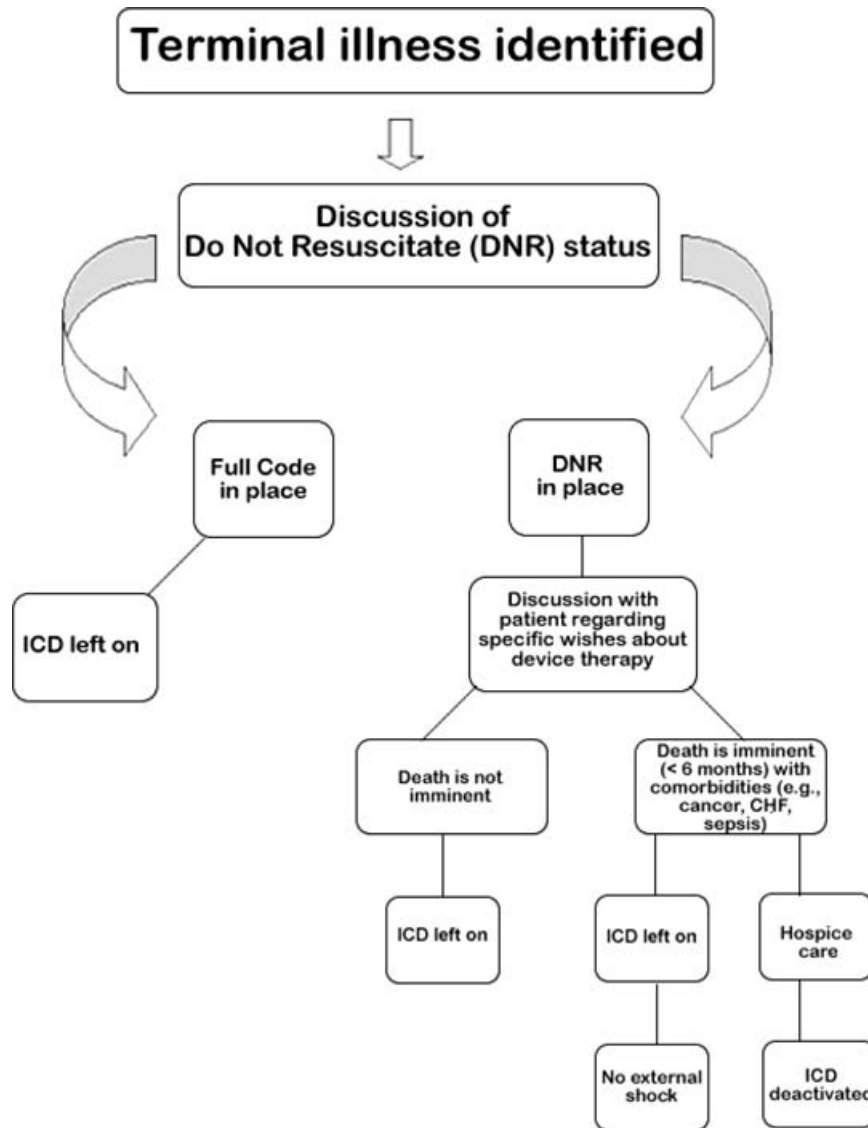
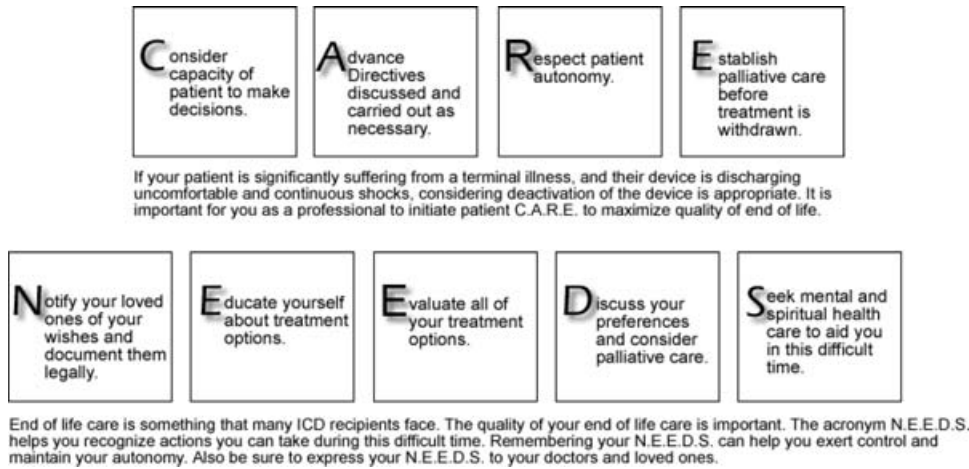


Figure 1. Palliative care decision-making tree.



**Figure 2.** Guidelines to help providers C.A.R.E. for patient N.E.E.D.S.

decision-making process, as EOL issues will inevitably become more salient. If a patient does opt for deactivation, establishing plans for EOL care can enhance QOD and provide a sense of comfort for the patient. Above all else, providers are encouraged to respect their patient’s right to make autonomous decisions.

From the patient perspective, EOL care involves the active consideration of all treatment options that increase patient control and ultimately increase QOD. Legal documentation is necessary and should be shared with loved ones in the event that questions or objections may arise. For many individuals, spiritual support and mental health

care may bolster QOD and remind patients of the qualities of their lives. Finally, patients should consider what palliative care options are available and what matches their needs best.

**Ethical and Legal Issues**

The impact of EOL care and considerations on family members is a poorly understood phenomenon. Although the lack of evidence in this area is clear, the limited existing research elucidates a desire on the part of families for health-care professionals to exert their expertise when dealing with EOL issues.<sup>23</sup> In the context of palliative care, hospice staff often observe the positive

**Table I.**  
Selections from Meisel et al.’s Myths and Facts Surrounding the Legality of Palliative Care

Myth	Fact
Health-care providers need written evidence in order to withhold life-sustaining interventions for incapacitated patients.	In most states, if a patient cannot make decisions on his or her own, a surrogate can relay the patient’s wish to stop life-sustaining treatment. Some states have a stronger burden of proof, though; health-care providers should therefore consult their state statutes for further information.
Verbal advance directives are not legally binding.	Oral directives can be legally upheld.
Advance directives are not transferable from state to state.	Many states do honor advance directives made in other states. However, in cases where such directives are not authorized out of state, an oral admission by the patient of his or her intent and wishes is acceptable.
Health-care providers must consult ethic boards or risk managers prior to stopping life-sustaining treatment.	Although such consultation may be beneficial in helping health-care providers understand their state’s mandate, the law does not require it. However, whether or not an individual hospital has internal regulations requiring physicians to seek consultation varies.

outcomes that effective EOL care provides. As a result, families may have less complicated bereavement and find more closure when they see their loved ones experience less sufferable, more peaceful EOL care.<sup>24</sup>

The hastening of death by device deactivation poses both ethical and legal issues; especially for families who are forced to act as surrogate decision-makers for loved ones incompetent to make EOL decisions for themselves.<sup>25</sup> In such situations, physician knowledge of said issues is essential in providing the most comprehensive EOL care to patients and families as possible. Professionals should be well aware of the legalities surrounding patient rights, evaluation of competency, powers of surrogates and proxies, and living wills.<sup>26</sup>

Meisel and colleagues<sup>27</sup> provide a thorough review of the legal implications of providing palliative care and the roles that health-care providers assume in assisting their patients with EOL issues. Myths and clarifications that directly relate to ICD recipients include concerns surrounding termination of device therapy, the applicability of advance directives, and physicians' roles in alleviating pain and discomfort. Table I presents a selection of such myths and facts reviewed by Meisel et al.<sup>27</sup> that may be particularly relevant to ICD recipients and their health-care providers.

A health-care provider who honors a patient's wish to terminate device therapy is not, in the eyes of the court, engaging in assisted suicide. In

*Washington v Glucksberg* and *Vacco v Quill*, the United States Supreme Court made the distinction between withdrawing life-sustaining treatment and physician-assisted suicide by noting that stopping treatment results in death by disease while administering drugs (e.g., morphine) results in death by practitioner.<sup>28</sup> Withdrawal of treatment has been deemed protected under the Fourteenth Amendment of the United States Constitution. Nonetheless, such action is only protected when consent is obtained either by the patient himself or by surrogates.<sup>28</sup>

### Conclusion

The recent high-profile legal cases about the right to die have infused the topic of treatment termination into our national psyche. The notion of having a satisfactory death may seem contradictory; human nature propels us toward life and vitality. These EOL issues represent a relative success for ICD technology by preventing premature death. For individuals with chronic and progressive illnesses like CHF, the ability to exert some control over the quality in which one faces the EOL is valuable. Rarely is the case that only the patient is affected by such decisions. Family members and loved ones require information and understanding from knowledgeable professionals to guide their actions. Even in the absence of family support, health-care professionals have a duty to provide communication about patient rights and wishes, legalities, and possible causes of action.

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