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- NYHA Class IV; discomfort with physical activity
- Symptomatic despite maximal medical management with diuretics and vasodilators
- Arrhythmias resistant to treatment
- Ejection fraction <20 percent

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## Patients with Advanced Heart Failure Need Earlier Discussion of Hospice Care

Elderly patients in the advanced stages of heart failure and their physicians face particular challenges unique to this disease, and these challenges make it difficult to determine when to discuss the initiation of palliative and hospice care, according to an invited review article published in the journal *Cardiology in Review*.

“The terminal stages of heart failure present challenges to both the patient and the clinician that are the equal of terminal cancer, but with facets that are unique to cardiovascular disease,” writes cardiologist John Arthur McClung, MD, professor of Clinical Medicine and Public Health, New York Medical College, Valhalla, New York.

Challenges faced by clinicians caring for these patients include:

- Prognostic uncertainty
- Episodes of acute decompensation that are often followed by relatively rapid improvement
- Increasing frequency of device therapy

McClung discusses the management of common symptoms such as dyspnea, pain, and fatigue, as well as the importance of treating comorbidities. Identifying psychosocial problems experienced by patients with advanced disease is also important, he notes. Physicians can elicit these problems by asking, “What are your three most troublesome problems?”

The article also addresses clinical and ethical issues surrounding such topics as the deactivation of device therapy, resuscitation status, and palliative sedation. But the focus

of McClung’s review is on the importance of timely discussion of palliative care, followed by its implementation.

“Palliative intervention for patients with heart failure, including hospice, is clinically indicated for patients presenting with progressively increasing pump failure,” states McClung. “What seems clear from the experience of many is that palliative care needs to be considered much earlier in the course of the disease process than is currently the case.”

Triggers for a discussion of palliative intervention include:

- A physician’s answer of “no” to the “surprise” question (“Would I be surprised if this patient died in the next 12 months?”)
- The occurrence of an acute exacerbation
- A lack of response to angiotensin converting enzyme inhibition
- The initial discharge of an automatic indwelling cardioverter defibrillator

“[P]atients dying of heart failure either do so suddenly, suffer a chronic, slow deterioration punctuated by acute episodes, or both,” McClung points out. “In either case, the physician will miss many opportunities to explore patient preferences in this population unless these preferences are addressed early in the course of the disease.”

*Source: “End-of-Life Care in the Treatment of Advanced Heart Failure in the Elderly,” Cardiology in Review; Epub ahead of print, August 7, 2012; DOI: 10.1097/CRD.0b013e31826d23ea. McClung JA; Department of Medicine, Division of Cardiology, New York Medical College/Westchester Medical Center, Valhalla, New York.*

# Many Patients and Surrogates Are Unprepared for Cardiac Device Deactivation

Most deactivations of cardiovascular implantable electronic devices (CIEDs) in terminally ill patients occur within days of death. Further, very few patients have written instructions in their advance directives (ADs) concerning their devices, and more than half of the requests for deactivation are made by their surrogates, according to a study conducted at the Mayo Clinic in Rochester, MN.

“Because hundreds of thousands of people in the U.S. have CIEDs, clinicians inevitably will encounter seriously ill patients with these devices who request device deactivation,” write the authors of a report published in *JAMA Internal Medicine*. “Although many patients with CIEDs have ADs, these documents rarely address device management.

“Patients with CIEDs should be encouraged to execute ADs with device-specific language to ensure that they receive care consistent with their preferences. This approach may reduce ethical dilemmas and moral distress among surrogates and care providers,” the authors state.

Investigators reviewed the medical records of 150 patients (median age, 79 years; male, 67%) who had their CIEDs deactivated by request at the Mayo Clinic during a 46-month period from 2008 to 2012. All patients but one (99%) had a poor or terminal prognosis. Overall, 79% underwent deactivation of tachycardia therapies only; 21% underwent deactivation of bradycardia therapies with or without tachycardia therapies.

## KEY FINDINGS

- More than half (57%) of patients in the study had an AD.
- Only one patient’s AD specifically mentioned the implanted device.
- 51% of deactivation requests were made by surrogates.
- Palliative medicine consultations were provided for 43% of patients; ethics consultations, for 2%.
- Median survival among patients with tachycardia deactivation only was significantly longer than for patients

## What Clinicians Can Say about Device Deactivation

- **At implantation:** “While the purpose of this device is to help you live a longer and better life, whether we like it or not, we all eventually die, and there will come a time when this device could be doing more harm than good. I want you to know that this device can be turned off at any time.

*“I encourage you to think about this ahead of time. Talk with your family, and write down your wishes in a living will or an advance directive. I’m committed to taking care of you for however long you have this device, and I’m happy to answer any questions you may have.”*

- **During routine follow-up:** “It looks like things are going well for you right now. As we’ve talked about before, there may come a time when this device is no longer helping you, or it might even become burdensome.

*“I don’t want to be morbid, but I just want to remind you that you have control here. We can turn the device off at any time. I’m committed to helping you, and I’m happy to answer any questions you may have.”*

— Matlock and Mandrola, *JAMA Internal Medicine*

with bradycardia deactivation (3 days vs 0 days). However, a similar proportion of patients in each group died within one month (85% vs 94%).

“Prior research has shown that most clinicians who care for dying patients with CIEDs regard device deactivation as allowing natural death rather than actively hastening death,” the authors note. They also point out that a 2010 consensus statement from the Heart Rhythm Society affirmed that CIED deactivation in seriously ill patients who no longer desire these therapies is both ethically and legally permissible.

“Notably, prior research has also shown that few patients with CIEDs know that device deactivation is an option and that many dying patients with implantable cardioverter-defibrillators experience shocks as they approach death.” The finding that the majority of deactivation requests were for tachycardia therapies alone suggests that patients or their surrogates wanted to avoid shocks during the dying process, they add.

## DISCUSSING DEACTIVATION

“[I]nitiating device deactivation discussions and helping patients consider their goals must be the responsibility of

all caring clinicians, especially caring electrophysiologists,” state the authors of a commentary accompanying the report. They note that it is unrealistic to expect specialists in palliative medicine to consult on every deactivation case. Such consultations are best reserved for difficult or tertiary cases.

**“If a clinician cares enough to learn and perfect the skills needed to implant a CIED, he or she must also care enough to help patients avoid harm and excess burden from the device at end of life.”** The commentators offer sample language clinicians can use to inform and support their patients. [See sidebar, above.]

*Source: “Features and Outcomes of Patients Who Underwent Cardiac Device Deactivation,” JAMA Internal Medicine; January 1, 2014; 174(1):80-85. Buchhalter LC, Ottenberg AL, Webster TL, Swetz KM, Hayes DL, Mueller PS; Mayo Medical School, Mayo Clinic College of Medicine; Program in Professionalism and Ethics, Mayo Clinic; Division of Cardiovascular Diseases, Mayo Clinic; and Division of General Internal Medicine, Mayo Clinic, all in Rochester, Minnesota. “The Antidote for Unprepared Patients: A Caring Clinician,” *ibid.*, pp. 86-87. Matlock DD, Mandrola JM; Division of General Internal Medicine, Department of Medicine, University of Colorado School of Medicine, Aurora; and Louisville Cardiology, Baptist Medical Associates, Louisville, Kentucky.*

# Patients Who Die in Hospitals Have Worse Quality of Life Than Those Dying with Hospice Care at Home

*Caregivers of hospitalized decedents have higher odds of developing bereavement-related psychiatric illness*

The place of death and type of medical care received by cancer patients near the end of life significantly affect the lives of both patients and their bereaved caregivers, a team of Boston researchers has found. Not only do those who die in hospitals have lower quality of life, but their caregivers have a five-fold greater risk of developing post-traumatic stress disorder (PTSD) following the death of their loved one.

“Where cancer patients die really does matter, not only for them, but for their family caregivers as well,” remarks lead author Alexi A. Wright, MD, instructor in medicine, Harvard Medical School and Dana-Farber Cancer Institute, Boston.

“This study provides evidence that patients with cancer who die at home have better quality of life at the end of life than patients who die in hospitals,” Wright and colleagues state in their report in the *Journal of Clinical Oncology*. “Patients’ experiences at the end of life have lasting effects on how their caregivers live after they are gone.”

The investigators conducted a prospective multisite study of 342 dyads of patients with advanced cancer (mean age, 58.0 years) and their caregivers (mean age, 51.3 years), as part of the larger Coping with Cancer study. Patients were followed from enrollment to death (median period, 4.5 months), with patient quality of life based on caregiver reports made within two weeks of death. Caregivers’ mental health was assessed from interviews conducted at baseline and again six months following the loss.

## **KEY FINDINGS AMONG CANCER PATIENTS:**

- There was no difference in patient survival by location of death.
- Patients who died in an ICU or hospital had lower quality-of-life scores than those who died at home with hospice services.
- Hospital and ICU decedents had higher

“Interventions aimed at reducing terminal hospitalizations or increasing the utilization of hospice services may improve the quality of life of patients with advanced cancer at the end of life and reduce the risk of psychiatric illness in bereaved caregivers.”

—Wright et al,  
*Journal of Clinical Oncology*

scores for both physical and emotional distress. These patients also had lower mean scores for physical comfort and for psychological well being.

- ICU decedents were less likely to have had an end-of-life discussion with a physician than were those who died at home.

## **KEY FINDINGS AMONG CAREGIVERS:**

- Caregivers of patients who died in ICUs had a heightened risk of developing PTSD compared with caregivers of patients who died at home with hospice (21.1% vs 4.4%; adjusted odds ratio [AOR], 5.00; 95% confidence interval [CI], 1.26 to 19.91).
- Similarly, these caregivers had higher odds of meeting criteria for prolonged grief disorder (PGD) — a period of intense, disabling grief lasting six months or more following loss — compared with caregivers of patients who died at home (21.6% vs 5.2%; AOR, 8.83; 95% CI, 1.51 to 51.77).

“Our study demonstrates that patients with advanced cancer who die in a hospital or ICU have worse quality of life at the end of life, and their caregivers have higher odds of developing bereavement-related psychiatric illnesses compared with those who die at home with hospice,” write the

authors. “These findings are important because patients with advanced cancer are receiving increasingly aggressive care at the end of life.”

## **RECOMMENDATIONS:**

### **INCREASED END-OF-LIFE DISCUSSIONS AND IMPROVED PATIENT EDUCATION**

“If patients are aware that the intensity of care that they receive near death may affect their quality of life — and that of their loved ones after they are gone — they may make different choices...so that they are protected against futile aggressive care,” observes Wright.

“Our findings suggest that interventions aimed at reducing hospital deaths or increasing hospice use may improve cancer patients’ quality of life near death, while also reducing the risk that caregivers will develop mental illness during bereavement.”

A member of the American Society of Clinical Oncology’s Cancer Communications Committee agrees. “As physicians, we can do a much better job of discussing end-of-life options for patients with advanced cancer,” says Jennifer C. Obel, MD. “These results show that there are real consequences to the choices made, in terms of quality of life for both patients and caregivers.

“We must approach educating patients about choices near the end of life with the same rigor that we approach educating them about treatment options like chemotherapy and surgery.” Obel practices hematology and oncology at NorthShore University HealthSystems, Evanston, Illinois.

*Source: “Place of Death: Correlations with Quality of Life of Patients with Cancer and Predictors of Bereaved Caregivers’ Mental Health,” Journal of Clinical Oncology; October 10, 2010; 28(29):4457-4464. Wright AA, Keating NL, Balboni TA, et al; Department of Medical Oncology and Center for Psycho-Oncology and Palliative Care Research, Dana-Farber Cancer Institute, Boston; Brigham and Women’s Hospital, Boston.*

## Patient-Reported End-of-Life Preferences Are Rarely Documented in Their Medical Records

Despite the wide acceptance of advance care planning and advance directives in the care of older patients, there is a disconnect between patients' stated wishes for end-of-life care and the care actually received. Researchers in Los Angeles have found that this may be due to a lack of information flow from patient to medical record.

"Preferences for end-of-life care among community-dwelling elders are often not available in medical record documentation" according to a report published in the *Journal of Palliative Medicine*. "In addition, patients do not consistently discuss end-of-life issues with their providers, even if they have thought about such issues."

The researchers examined data from two previous quality of care evaluations, the Assessing Care of Vulnerable Elders (ACOVE)-1 and ACOVE-2, consisting of a total of 811 community-dwelling elders (mean age, 81 years).

### KEY FINDINGS INCLUDE:

- The vast majority of patients participating in the survey said they preferred to die rather than remain permanently unconscious (93%), indefinitely attached to a ventilator (90%), or fed through a tube (88%).
- 38% said they had thought about limiting the aggressive care they would receive at the end of life, and 24% said they had spoken to their physician about this.
- Despite these stated preferences, only 15% to 22% of respondents had such preference information in their medical records.
- Among those respondents who reported having completed an advance directive and given it to their health care team, only 15% (ACOVE-1) and 47% (ACOVE-2) had such information in their medical record.

"The uniqueness of patients' preferences, coupled with the frequent desire to avoid certain medical interventions, reinforce the need to assess older adults' preferences regularly and to document them," comment the authors.

"Documentation is...critical in a health care system that relies on teams of providers in different settings," they assert. "Future research should address whether electronic health records and/or a structured approach to documenting patients' preferences, such as the Physician Orders for Life-Sustaining Treatment, could reduce these problems..."

Source: "Documentation of Advance Care Planning for Community-Dwelling Elders," *Journal of Palliative Medicine*; July 2010; 13(7):861-867. Yung VY, et al; David Geffen School of Medicine, University of California, Los Angeles; Health Services Research & Development Center of Excellence and Geriatric Research, Education, and Clinical Center, Veterans Affairs Greater Los Angeles Healthcare System; University of California, Los Angeles Healthcare Ethic Center, Los Angeles, California.

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