National Hospice & Palliative Care Organization

POSITION STATEMENT ON THE CARE OF HOSPICE PATIENTS WITH AUTOMATIC IMPLANTABLE CARDIOVERTER-DEFIBRILLATORS

In 2005, the Center for Medicare & Medicaid Services expanded the coverage criteria for automatic implantable cardioverter-defibrillators (AICDs) (Centers for Medicare & Medicaid Services [CMS], 2005). The clinical benefit and the expanded coverage for this intervention has resulted in a marked increase in the number of implanted AICDs (CMS/Iowa Foundation for Medical Care, 2006; Hammill et al., 2007), and hospices are now very likely to be caring for patients with these devices. Terminally ill patients face the risk of AICD discharges during the dying process (Goldstein, Lampert, Bradley, Lynn, & Krumholz, 2004). Such discharges may not be consistent with patients' goals of care and can be the source of significant and preventable distress to both patients and caregivers.

The National Hospice and Palliative Care Organization (NHPCO) and the National Quality Forum (NQF) promote palliative care that incorporates "anticipating" and "preventing" suffering as well as "facilitating patient autonomy, access to information, and choice" (National Quality Forum, 2006, p. 3). Deactivating an AICD prior to the dying process could prevent foreseeable pain and distress from non-therapeutic AICD discharge for patients and their caregivers. The following six recommendations for treating hospice and palliative care patients with AICDs adhere to these guiding palliative care principles. These guidelines address AICDs or the defibrillator function of dual AICD/pacemaker devices only. They are not intended to apply to pacemakers or the pacemaker function of dual devices.

1. **All patients with AICDs should be identified on admission and this should subsequently be documented prominently**. All patients and their designated caregivers[*] should be asked specifically about the presence of any implanted medical devices. Admissions nurses should conduct a thorough physical exam to identify the possible presence of such devices. Documentation of the device type, manufacturer, and model is recommended.

[*] Use of the term "designated caregiver" in this document refers explicitly to the person appointed by the patient to be the patient's surrogate decision maker in all matters involving health care. At the patient's discretion, any other persons who are a part of the patient's circle of care may also be involved in care discussions and decisions.

2. **The possibility of AICD discharge during the dying process should be thoroughly explained to patients and their designated caregivers as early as possible after admission to a hospice or palliative care program**. Patients should be asked if they have experienced AICD discharges in the past. If so, any future discharges are likely to evoke a similar experience. If the AICD has never discharged, then a detailed description of the likely experience should be related to patients and their designated caregivers.

3. **The option of deactivating AICDs should be thoroughly explored with patients and their designated caregivers as soon as possible after admission**. The goals of care surrounding the initial implanting of the AICD should be ascertained, and the team should discuss whether patients still desire the presence of a functioning AICD. This discussion would highlight the possible benefits and burdens of the device given the current condition of, and prognosis for, each patient. Patients' values and goals of care will ultimately inform the decision-making process and certainly may change over time. A decision not to deactivate an AICD must be respected by the team, although this can always be revisited—especially after any changes in patients' conditions.

4. **Patients, their designated caregivers, and healthcare team members should be educated that deactivation of an AICD does not constitute euthanasia or physician-assisted suicide, nor is it likely to hasten death.** The deactivation of an AICD is ethically equivalent to the voluntary withholding or withdrawing of treatment (Ballentine, 2005; Derse, 2005; Mueller, Hook, & Hayes, 2003). This deactivation will not result in the immediate death of the patient, just as device discharge in a dying patient will not restore the patient to a state of health. Rather, deactivation simply removes the discharge intervention of AICDs should patients experience a detectable dysrythmia. Admissions nurses and other relevant interdisciplinary team members should receive specialized training in having conversations with patients and their designated caregivers about AICD deactivation.

5. **Patients, their designated caregivers, and healthcare team members should be informed about any decision to deactivate an AICD and about the methods to achieve deactivation.** An AICD can be deactivated in physicians' offices or in patients' homes with an appropriate physician's order. The pacemaker function of the device, if present, may be left intact. The AICD can also be emergently and temporarily disabled by holding a suitable magnet on the skin over the implanted AICD, if this is the desire of the patient or designated caregiver. The device will reactivate if the magnet is removed or displaced, and magnet placement should not be considered a substitute for deactivation by a trained professional. Home-bound patients who wish to deactivate their devices have a right to deactivation in the home by qualified professionals specifically trained in device deactivation. Hospice agencies are encouraged to proactively identify and engage local professionals trained in and qualified for deactivation who are willing to travel to patients' homes to deactivate AICDs.

6. **The process of AICD identification, education of the involved parties, discussion about goals of care, and possible device deactivation should be incorporated smoothly into current hospice and palliative care practices.** Hospices should establish procedures and protocols that will readily and consistently provide available safeguards for patients with AICDs. Ongoing internal data collection is encouraged to monitor the effectiveness of policies in achieving three minimum outcomes:
   - **(a)** all patients with AICDs are identified;
   - **(b)** all hospice clinicians, AICD patients, and their designated caregivers understand the possibility of discharge and the option to deactivate the device;
   - **(c)** all patients, including home-bound patients, who choose to deactivate their AICDs have access to timely deactivation by qualified clinicians.

Approved by NHPCO board of directors and released, May 2008.

Works Cited

Ballentine, J. M. (2005). Pacemaker and defibrillator deactivation in competent hospice patients: an ethical consideration. *American Journal of Hospice & Palliative Care 22*(2), 14-19.

Centers for Medicare & Medicaid Services (2005). *NCD for implantable automatic defibrillators*. (CMS Publication No. 100-3, Transmittal 29, Change Request 3604) Baltimore, MD: Centers for Medicare & Medicaid Services.

Centers for Medicare & Medicaid Services/Iowa Foundation for Medical Care (2006). *Implantable cardioverter defibrillator (ICD) implantation data* [data file]. Available for purchase from CMS web site, http://www.cms.hhs.gov.

Derse, A. J. (2005). Limitation of treatment at the end-of-life: withholding and withdrawal. *Clinics in Geriatric Medicine 21*(1), 223-238.

Goldstein, N. E., Lampert, R., Bradley, E., Lynn, J., & Krumholz, H. M. (2004). Management of implantable cardioverter defibrillators in end-of-life care. *Annals of Internal Medicine 141*(11), 835-838.

Hammill, S. C., Stevenson L. W., Kadish, A. H., Kremers, M. S., Heidenreich, P., Lindsay, B. D., et al. (2007). National ICD Registry annual report 2006: review of the registry's first year, data collected, and future plans. *Heart Rhythm 4*(9), 1260-1263.

Mueller, P. S., Hook, C. C., & Hayes, D. L. (2003). Ethical analysis of withdrawal of pacemaker or implantable cardioverter-defibrillator support at the end-of-life. *Mayo Clinic Proceedings 78*(8), 959-63.

National Quality Forum (2006). *A national framework and preferred practices for palliative and hospice care quality*. Washington, DC: National Quality Forum.