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Letter to the editor

EOL considerations in defibrillator deactivation

To the editor:

I read with interest the article by Jennifer Ballentine on ethical considerations regarding defibrillator deactivation (January/February 2005, pp. 14-19). We had a patient who went home with home hospice. The defibrillator was never turned off. As a result, the wife reported that the patient died in her arms while the defibrillator jolted him 33 times before the battery ran down. She stated that the defibrillator got so hot that it burned through his skin. Needless to say, this greatly distressed his wife. She's had difficulty getting this memory of her last moments with her husband out of her mind.

As a result, we worked with our community hospice to develop education about deactivating defibrillators. I also phoned the three major manufacturers of defibrillators (Medtronic, Guidant, and St. Jude Medical) to assess what information they provide to patients and families. I was told that patient education was "not our job; that's the doctor's job." They were speechless when I asked what information they provided the doctors so the doctors could then inform patients. None of their printed materials addresses this issue—either for patients or for physicians. I have since encountered numerous patients with implanted defibrillators. Not one has reported that their physician addressed end-of-life issues regarding the defibrillator.

My letter contains more questions than answers or opinions: How can

patients make an "informed consent" if they do not have all the information? Are patients told that one of the possible adverse effects of the defibrillator is that their death might involve getting shocked 33 times while their loved ones watch in horror? Whose job is it to provide patient education about associated EOL concerns—the implanting surgeon? The attending physician? The defibrillator company? The hospice? Doesn't the manufacturer have an ethical and legal obligation to address this issue in its printed materials? Should the National Hospice and Palliative Care Organization (NHPCO) be taking an ethical stand to address issues that complicate patient deaths? Should patients and family members be given a magnet to deactivate the defibrillator when they enter hospice or at least be told where to get one? Should surgeons and manufacturers be forced to watch a person get shocked 33 times as they die so they might then accept responsibility for providing informed consent?

I hope our professional journals and organizations will provide leadership for the rest of us on this important ethical issue.

Deborah Grassman, ARNP
VA Hospice
Bay Pines VA Medical Center
Bay Pines, Florida

Author reply

To the editor:

The appalling situation described by Ms. Grossman is exactly the scenario I

would hope to prevent by raising awareness around deactivation of defibrillators, specifically in terminal patients. Her questions are challenging, and to answer them in depth would require another article. Instead, I'll focus on the ethical questions she raises, in particular the ethical obligations of informed consent.

First, I will say that there are clearly as many questions about the ethics of defibrillator/pacemaker *implantation* as about deactivation—education around end-of-life issues being only one of them. As a practical matter, "informed consent" is never *fully* informed. Ethically, the obligation is to provide information sufficient for the patient to assess likely risks, burdens, benefits, and consequences of the intervention. It is impossible for any healthcare professional to offer all the information available, so judgment must be exercised about what information to offer in what way, always with the objective of facilitating the patient's decision making rather than imposing a preference.

What is often neglected in this equation is the contextual ground for the decision—the patient's goals. Given the same information about a defibrillator, patient A, whose goal is to keep on living and playing golf as long as possible, will make a very different decision than patient B, whose goal is to experience a pain-free, unimpeded, natural death. Patient A may very well become patient B over time—at that point, information about the possible negative action of the defibrillator becomes keenly relevant. The function and action of the device has not changed; rather, the patient's

goals have. This requires a new consideration of the same set of factors and, likely and appropriately, a decision to deactivate.

Thus, informed consent is not solely a matter of information but a matter of what information is given at what time, in what way, and in what context. Although cardiologists, surgeons, attending physicians, and manufacturers "should" address EOL concerns, it is my contention that hospices *must* address the possible consequences of defibrillator function in the

dying process because the context demands it. My article suggests a process for doing that, preferably on admission. Whatever may or may not have been discussed 10 years ago when the device was implanted, the issues must be raised and resolved in the hospice setting.

As to the NHPCO taking an ethical stand, I would strongly urge the national ethics committee to survey hospices on their toughest ethical issues (palliative sedation, withdrawal of artificial nutrition and hydration, cardiac device

deactivation, and boomerang discharges are just a few that immediately come to mind) and develop model policies or deliberative protocols around them: not to impose a particular resolution, but to guide ethics committees, interdisciplinary care teams, physicians, nurses, patients and families in their own considerations of these very tough issues.

Jennifer Ballentine, MA
Chair, Metro Denver End-of-Life
Coalition
Denver, Colorado

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The *Journal* welcomes letters on subjects related to all aspects of hospice or palliative care. Letters in response to articles in specific issues of the *Journal* are especially welcome, but, to ensure timely publication, they should be sent soon after distribution of the issue in question.



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Letter to the editor

American Journal of Hospice & Palliative Medicine

470 Boston Post Road

Weston, MA 02493

Fax: 781-899-4900

E-mail: hospice@pnpc.com