“Legality and Ethics Can Create Misperceptions,” in the current Hospice Management Advisor, looks at how conflicting opinions between advance directives, healthcare proxies, and families can create complex scenarios at the end of life. Nancy M.P. King, JD, is a professor in the Social Sciences and Health Policy Department at Wake Forest University, and co-director of the WFU Center for Bioethics, Health and Society. King says that one common situation occurs when either the advance directive or the healthcare proxy, or both together, think that one action is the best, while someone in the family objects.

A team member may think “that the best way not to get sued is to follow the family members’ wishes.” Another may think that if the family wants the patient kept alive, that’s what should happen. According to King, there is “very little case law saying that somebody who fails to honor an advance directive and keeps the patient alive longer has actually done cognizable harm to a patient that can be effectuated through a lawsuit.” A team member, trying to avoid being sued, may choose care that conflicts with an advance directive, because “nobody’s ever going to bring that lawsuit, and they may not sue, because the patient was kept alive and because it’s very difficult to bring lawsuits like that.”

King says that this is a bad decision. “This is . . . a situation where somebody is really expecting that it is really possible to keep everything quiet by doing something that’s morally wrong.” Situations like these may make it appear that law and ethics are not compatible but, she says, this isn’t the case.

The advance directive should be honored, according to King. “The right way to proceed with a situation like that isn’t to say, ‘Hey, law is on our side, as well as ethics,’ but to sit down with the family and really, again, take that initial time. One of the reasons why it’s easy to … try to take mental shortcuts and say there’s an incompatibility here is that the best way to address perceived incompatibilities like that is very time-consuming and involves some very difficult conversations.”

Alexander A. Kon, MD, director of the clinical bioethics consultation service at UC Davis Medical Center, says that one place where law and ethics don’t necessarily go hand-in-hand is in physician-assisted dying. Only three states now allow physician-assisted death, but if a patient in another state wants a lethal dose and a physician thinks it’s the right thing to do, it’s still illegal.
Paula Goodman-Crews, regional bioethics director of the Southern California Region of Kaiser Permanente, says that saying that physician-assisted dying is illegal in the other 47 states ends the “legal portion” of the discussion. But, she adds, “This gets into really kind of frightening territory, where there are physicians, especially, I would say, hospice physicians, who almost on a daily or weekly basis are probably approached by patients or family members asking, ‘Please, can you do something?’”

Physicians in states without PAS laws have to respond that they cannot prescribe lethal doses, but what happens if the patient stockpiles enough pain medication to take their own lives? Or if a patient with a DNR order tries unsuccessfully to commit suicide and is brought into the hospital? Goodman-Crews says that you have “competing ethical obligations.” If you respect the patient’s autonomy, you may be helping complete the suicide. If not, you are violating the advance directive with the DNR. (Hospice Management Advisor, 6/1; www.thefreelibrary.com/Legality+and+ethics+can+create+misperceptions-a0228825610)

HOSPICES CALLED TO ADDRESS ICD DEACTIVATION WHEN LIFE IS SHORT

Several articles in the current Hospice Management Advisor address the issue of patients with implantable cardioverter-defibrillators (ICDs). “Are You Talking to Patients About Deactivation of Their ICDs?” says that patients can die in a lot of pain if their ICDs are still functioning as they are dying. A recent study from the Hertzberg Palliative Care Institute at Mount Sinai School of Medicine found that 97% of hospices admit patients with ICDs. But only 20% of these hospices identify these patients on intake, and only 10% have policies regarding discussions of deactivation.

Dr. Nathan Goldstein, lead author of the study, says, “There is a clear link between the identification of a patient with an ICD, a policy guiding discussions about deactivation, and a higher rate of deactivations. It makes sense that a hospice that has thought about the effects of an ICD’s shock at the end of life is better equipped to initiate the conversation with patients and family members.” Goldstein thinks the patient is unlikely to initiate such a discussion, because they may not know that the device can be deactivated.

Dr. Chuck Wellman, chief medical officer at Cleveland’s Hospice of the Western Reserve, says that more patients have pacemakers than ICDs, “but a pacemaker doesn’t deliver a high voltage shock that causes pain, so that device is not the burden that an ICD is.” Wellman also says, “It is difficult when the patient does not want the ICD deactivated and the family does. Family members suffer a great deal of stress and anxiety watching their family member suffer pain, so they are more likely to want the deactivation.” The role of the hospice staff, in his opinion, is “to provide information, moderate the discussion, and honor the patient’s wishes.”

“How to Initiate a Difficult Conversation” says that the best time to discuss deactivation is when the device is implanted, but that it rarely happens. Once a hospice patient is admitted, the admitting nurse should get information about the manufacturer and type of device. The devices can have four functions, depending on the patient’s needs:

* **Pacing**: A few pacing signals are given with mild tachycardia;
* **Cardioversion**: A mild shock is given if pacing stops;
* **Defibrillation**: A large shock if ventricular fibrillation occurs, and
* **Pacer**: A set number of beats per minute are given if bradycardia occurs.

Janet Bull, MD, chief medical officer of Four Seasons Hospice & Palliative Care in Flat Rock, North Carolina, says that deactivation is simple, painless, and non-invasive. She adds, “We explain that we can disable the shocking component without disabling the pacer component. It is also important to point out that deactivation is consistent with a do-not-resuscitate order.”

Goldstein concludes, “This is a difficult conversation for any health care provider to have with patients and families, but hospices are good at difficult conversations. It’s important to have policies that make sure these conversations take place.”

Another article, “Policy Should Outline Steps for Deactivation,” discusses the policy in use at the Hospice of the Western Reserve. Patients with ICDs are discussed in team meetings, including the patient’s advance directives and the “benefits and burdens” of an ICD for that patient. If the device is to be deactivated, an order must be gotten from the physician. If there is no emergency, the manufacturer’s representative is asked to deactivate the device. Otherwise, a nurse tapes a magnet to the patient’s chest – removing the magnet will allow the ICD to resume functioning. Nurses are also responsible for notifying funeral homes of ICDs. One spokesman explained that they may explode during cremation. *(Hospice Management Advisor, 6/1, www.thefreelibrary.com/How+to+initiate+a+difficult+conversation.-a0228825619; www.thefreelibrary.com/Policy+should+outline+steps+for+deactivation.-a0228825611; www.thefreelibrary.com/Are+you+talking+to+patients+about+deactivation+of+their+ICDs%3f-a0228825612)*

**RESEARCH & RESOURCE NOTES**

* “Quality of Care – How Good is Good Enough?,” in the current *JAMA*, says “The methods for setting a threshold for acceptable care are still rudimentary.” Even setting a threshold level is a poor way to decide, and the authors recommend “reframe[ing] the problem in clinical terms, as an individualized decision between adhering to the guideline or deviating from it.”

“An alternative, simpler approach would be to avoid thresholds altogether by using decision quality as the sole measure of quality. A threshold level of adherence to a practice guideline is necessary to define the minimal acceptable practice while acknowledging that perfect adherence is not necessary or even desirable. Because a well-informed decision is always better than a poorly informed one, physicians should always strive for good decision quality. Therefore, thresholds would be unnecessary if decision quality were the measure of practice quality.” *(JAMA, 2010,303(23):2403-2404)*

* An article in the May *Journal of the American Geriatrics Society*, “End-of-Life Care Preferences and Planning of Older Latinos,” examines the preferences for end-of-life care, the extent of advance care planning, attitudes about patient autonomy, the role of the family in decision-making, and trust in healthcare providers among older Latino patients. Eighty-four percent of respondents would want comfort care rather than life-extending care if they were seriously ill, but 77% had no advance care plans and 47% had not discussed their preferences with their family or their doctor. Sixty-four percent preferred family-centered decision-making, and 63% approved of limited patient autonomy. *(Journal of the American Geriatrics Society, 2010,58(6):1109-1116, dx.doi.org/10.1111/j.1532-5415.2010.02853.x)*
* “Documentation Presents Challenges at Hospices,” in the current Hospice Management Advisor, reviews an article originally published in the Journal of Hospice & Palliative Nursing. The article emphasizes the necessity of “documentation of all aspects of nursing care” in the current regulatory and legal environment. A wide variation in standards and practices was found in the study. The authors say that “uniformity in key practice indicators and patient outcome measures in documentation systems are needed to improve quality and consistency of care in hospices,” and also recommend “standardization of documentation systems and language to facilitate research in the hospice setting.” (Hospice Management Advisor, 6/1, www.thefreelibrary.com/Journal+Review%3a+Documentation+presents+challenges+at+hospices.-a0228825614; Journal of Hospice & Palliative Nursing, 2009, 11:334-341)

* Cahaba GBA has recently published suggestions for improving documentation. The suggestions are online at the link below. (Cahaba GBA Website, www.cahabagba.com/rhhi/education/materials/quick_hospice_doc.pdf)

**OTHER NOTES**

* Montana Governor Brian Schweitzer (D) recently visited Montana Pain Management, a Missoula “cannabis facility,” to discuss what sort of regulations need to be enacted to control medical marijuana. According to Schweitzer, medical marijuana was “just a concept” when the voters approved it. He adds, “We didn’t put the boundaries in at that time and now the business has gotten out ahead of regulatory environment …” The same week of the Governor’s visit, Cannabis Science Inc., a “pioneering US biotechnology company working with global authorities to develop pharmaceutical cannabis products,” announced that it is buying Montana Pain Management. (KBZK, 6/18, www.kbzk.com/news/governor-visits-missoula-medical-marijuana-shop; International Business Times, 6/17, www.ibtimes.com/articles/29259/20100617/cannabis-science-inc-cbis-ob-announces-its-next-acquisition.htm)

* Denice Economou, senior research specialist and project director for survivorship education for quality cancer care at California’s City of Hope, was recently interviewed about the psychological aspects of pain management. She sees the biggest obstacles to good pain management as “fear of addiction and not understanding what pain management consists of.” City of Hope uses the “multimodal” approach, which combines adjuvant medications, nonpharmacological therapies, and management of psychosocial issues. (Medscape Today, 6/17, www.medscape.com/viewarticle/723724)

* Dr. Jack Kevorkian says that he regrets nothing he did in helping several patients end their lives. He admitted, however, to MSNBC newsperson Rita Cosby that “the only regret he might admit to is not working through the legal system to allow physician assisted suicide for patients who ‘qualify.’” The article says, “Kevorkian also compared himself and his ‘quest’ to that of a soldier in Iraq, saying if he was technically a ‘killer’ for helping a patient die, then ‘so is every soldier in Iraq now a killer’ - as if the two were remotely connected.” (The Post Chronicle, 6/15, www.postchronicle.com/news/strange/article_212307344.shtml; www.msnbc.msn.com/id/9532036/ns/msnbc_tv-rita_cosby_specials)
* Actor Gary Coleman, who died last month, had a living will and a healthcare proxy. His living will expressed his wish to be kept alive in a coma for at least two weeks, but his proxy, who was his ex-wife, had his life support discontinued after one day. State laws vary as to how much weight a living will carries vs. a healthcare proxy, and information specific to each state is available at www.caringinfo.org. The article suggests reviewing advance directives periodically to make sure that the person named as a proxy is still the person you want to carry out your wishes. (CNN Health, 6/16, www.cnn.com/2010/HEALTH/06/16/living.wills.coleman/)

* “Getting On With Life After a Partner Dies,” in The New York Times, is Health Editor Jane Brody’s story of adjustment after her husband died. She says that people who adjust well “have what experts call ‘psychological resilience’ — the ability to take life’s blows in stride and get on with it rather than dwell on the pain of loss, no matter how challenging it may seem at first.” She agrees with Joan Didion that the emotional adjustment is the most difficult, at least at first.” (The New York Times, 6/14, www.nytimes.com/2010/06/15/health/15brod.html)

* Alex Tyree was a chaplain and a bereavement counselor for Delaware Hospice. His work, and that of the Hospice, was profiled in Episcopal News Monthly after his death from cancer. A prior executive director of the hospice said, “Delaware Hospice is a wonderful example of how the diocese, with some seed money and some key people, can mobilize to meet a major need.” (Episcopal News Monthly, 6/2010, www.dioceseofdelaware.net/communion/2010/2010_06_DelawareCommunion.pdf)

* A news release from the University of Virginia noted the passing of Dr. Carlos F. Gomez, hospice and palliative care pioneer. Gomez was the first medical director of the University of Virginia Health System's Center for Hospice and Palliative Care, and most recently the medical director of the District of Columbia Pediatric Palliative Care Collaboration. Gomez also appearing in “On Our Own Terms,” Bill Moyer’s PBS special on dying in American which aired in 2000. (UVA Today, 6/17, www.virginia.edu/uvatoday/newsRelease.php?id=12181)

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