HOSPICE NEWS NETWORK

What the Media Said about End-of-Life Care This Week

Volume 14, Number 38  September 28, 2010
A Service of State Hospice Organizations

HOSPICE POLICIES AND PHYSICIAN-ASSISTED DEATH

In “Hospice and Physician-Assisted Death: Collaboration, Compliance and Complicity,” the current Hastings Center Report examines the “legal and moral questions [that] prevent hospices from collaborating fully with physician-assisted death.” The study of 55 Oregon hospices revealed a variety of philosophies, procedures and practices when patients request a physician-assisted death.

The Oregon Hospice Association says that terminally ill patients shouldn’t feel compelled to “choose between hospice and physician aid-in-dying.” It further says that “a hospice should never deny a person its services because he or she has asked a doctor for a prescription.” In practice, however, most Oregon hospices “set programmatic, professional and moral boundaries to their involvement in physician-assisted deaths, and many of them do not participate in most or all features of implementing physician-assisted death under Oregon law.” Also, most hospice programs in the state “treat deaths attributable to physician-prescribed medicines differently than other deaths they attend.”

The authors of the article say that there are some tenets in the core values of hospice that are in tension with physician-assisted death:

1) Hospices work to neither hasten nor prolong death, while physician assisted suicide (PAS) does hasten death. “Reconciling the commitment not to hasten death with patient requests for physician assistance in obtaining medication to hasten death”;
2) Hospice makes a commitment to remain with, rather than abandon patients. But avoiding involvement with the act of PAS does require distancing from the patient. “Reconciling the commitment not to abandon patients and their families with the general posture of avoiding involvement with medication or assistance regarding the act of medication ingestion,” and
3) Hospice relies on an interdisciplinary team, while PAS falls within the physician-patient relationship. “Reconciling the commitment to respect the integrity of the physician-patient relationship for patients who request physician-assisted death with the interdisciplinary and holistic mode of hospice care that involves nurses, social workers, spiritual care counselors, and others.”

Though “all Oregon hospice programs promise ‘standard hospice services’ to all patients,” the survey revealed significant differences. The only issue on which they are all united is that none will provide the needed medication to end life, nor will they allow staff to participate in administering that medication.

1) Hospices show variances in language “to describe the act of a hospice patient obtaining a physician’s prescription to end life.”
2) Hospices demonstrate differences in how, and how much, information they provide to patients regarding PAS.
3) Hospices vary in terms of how they relate to the patient’s attending physician, who is the one who will write the prescription.
4) Hospices vary one from another in allowing hospice staff to be present during PAS.

Different philosophies emerge when the nuances of the above positions are examined. For instance, some hospices refuse to provide any information about physician-assisted death, perhaps for religious reasons. These programs are a minority, and most will provide some degree of information. Some provide only information about the Death With Dignity Act and the rules for obtaining medication. Others allow a dialogue in which the patient’s interest in physician-assisted death is explored. Such dialogues allow a “procedural safeguard” because they provide a means of determining whether inadequate hospice care is a reason for the patient’s interest in hastening death.

Many hospices that do allow dialogues with patients requesting physician-assisted death require that staff maintain a neutral position. The goal in this case is for the patient to make an informed decision according to his or her own values, not those of the hospice staff. The authors write, “The concept of ‘neutrality’ … is the communication analog to hospice’s philosophical commitment that death is neither to be hastened or postponed; moreover, it allows those hospice programs concerned about complicity in physician-assisted suicide to minimize their role and influence in a patient’s choice.”

Another key issue explored in the article is the prohibition of hospice staff attending an assisted death. One central tenet of hospice is not to abandon the patient at the time of death, and some hospices believe that hospice policies should not only permit attendance at an assisted death, but should require it. In Oregon, 31 of the 55 surveyed hospices prohibit it, 11 permit it, and 12 have no statement about it.

The article says that it is not clear which hospice statements and policies are “so compromised by staff presence that it warrants prohibiting staff presence.” Having a staff member present at death neither violates the prohibition of hastening death, nor does it mean that hospice care will cease for the family when the patient takes the medication. Since hospice staff would normally attend the death of any other patient if asked to do so, the authors ask how physician-assisted death is “morally and vocationally different from any other kind of death?”

Hospices have two principal concerns about allowing staff members to be present at assisted deaths. One is that having hospice personnel present at ingestion “can create a public perception that hospice encourages or endorses physician-assisted death, or even that the hospice may be responsible for ensuring that physician-assisted death happens without any complications.”

Second, about 5% of the time, a “post-ingestion complication” occurs, usually when the patient vomits up the medicine. Some feel that a hospice care provider would feel obligated to intervene, perhaps by providing anti-nausea medicine. “In this scenario, the hospice staff member could plausibly be understood to have assisted in bringing about death, violating a hospice prohibition on assistance and potentially contravening the law.”

In the respondents to the survey, the authors found four actual hospices that represent the models of hospice participation under the law.
1) “Full participation within the parameters of the law.” If a patient inquires, information is provided and patients are directed to contact their attending physician who will
prescribe or referred to an organization who will help them find one. Staff members may attend the death, but will assist only in the “human” patient needs, leaving the “medical” needs to the physician who prescribes the medication

2) “Moderate participation:” Information is provided if requested, but only certain staff members can discuss it with the patient. Staff members are required to be neutral. The patient is directed to speak with the attending physician, but no referral information to educational organizations is permitted. If requested by the family or patient, staff may attend the death.

3) “Limited participation:” Patients are referred to attending physicians without conversation. No assistance is given the patient, and staff members may not be present when the medication is taken. The hospice will continue to care for the patient rather than arranging for care to be transferred to another hospice, and will provide bereavement services.

4) “Nonparticipation or noncooperation permitted by law:” This hospice considers physician-assisted death to be physician-assisted suicide. No information is given, no referrals to physicians are made, and staff may not be present when the medication is ingested.

The authors cite the work of Timothy Quill and Christine Cassel in recommending “studied neutrality” as the position compatible with most Oregon hospices. The goal of studied neutrality is to “recognize the diversity of views among patients and providers and encourage open discussion of the issue.” It also “avoids the moral obfuscations that occur when hospice programs assert that they are not ‘directly’ or ‘actively’ participating in the law, and it can be a remedy for the many times in hospice care when issues of moral complicity surface.” (Hastings Center Report, 9-10/2010)

RESEARCH & RESOURCE NOTES

* The American Pain Foundation has launched “PainSAFE,” a web-based initiative that offers up-to-date information, practical resources and tools to inform consumers about pain treatment options and their safe use. It also includes a central hub of evidence-based information and practice-based tools for health care providers.” (American Pain Foundation, www.painsafe.org)

* A study that will be published online ahead of print in the American Journal of Respiratory and Critical Care Medicine reports on a failed intervention to improve communication and satisfaction of families of patients who died in critical care settings. Twelve hospitals in the Seattle-Tacoma area participated. Those who got the intervention had staff training for doctors and nurses in increasing communication, and staff members were told to discuss end-of-life issues openly with families. Surveys after the death of the patients found no measurable difference in satisfaction of families between the two sets of hospitals. (NewsRx Health, 10/3)

* In spite of its rather lurid title, No Good Deed: A Story of Medicine, Murder Accusations, and the Debate Over How We Die is “a finely nuanced examination of the controversies surrounding palliative and end-of-life care.” Author Lewis Cohen, psychiatrist and palliative care specialist, says, “The focal point of this book is accusations over clinical procedures and decisions considered by most authorities and medical organizations to be both legal and ethical.” In the beginning, Cohen warns readers that many medical professionals are “unappreciative of the fact that what they perceive to be ordinary clinical care can trigger criminal proceedings …the possibility of bankruptcy, imprisonment, and the total obliteration of their medical careers.” He concludes by saying, “My chief hope is that the public discourse will quickly move beyond emotionally based arguments and murder accusations. Instead, a meaningful dialogue that
produces thoughtful and balanced policies is desperately needed.” (JAMA, 2010,304(12):1389-1390, dx.doi.org/10.1001/jama.2010.1384)

* “Exploring Factors that Influence Informal Caregiving in Medication Management for Home Hospice Patients” reports on a Chicago-area study of caregivers and hospice providers regarding management of medications at home. Caregivers with high self-confidence were less afraid of making medication errors, and some life experiences of caregivers provided skills in managing medications beyond those hospice would teach. Both the caregivers and hospice providers identified negative emotional states of caregivers, such as grief and fatigue, as limitations to medication management by caregivers. Other obstacles included cognitive impairments, such as failure to remember what the nurses said about the medication, and physical impairments, such as the inability to see how much medication is being measured, and other responsibilities. Caregivers mentioned the negative emotional states of patients as a problem. Both groups identified patience, good relationships and communications as helping patients accept care. (Journal of Palliative Medicine, 2010,13(9):1085-1090, dx.doi.org/10.1089/jpm.2010.0082

CMS AND HOSPICE NOTE

* A publication from CMS’s Survey & Certification Group has extended the time in which hospices can qualify for an “extraordinary circumstance” because the health care shortage has affected their ability to hire nurses. S&C-02-44 originally gave the deadline as September 30 of this year. The new communication, S&C-10-31-Hospice, extends it until September 30, 2012. Hospices must notify their State Survey Agency that they intend to elect an exception, and must estimate the number of contract nurses needed. Information included in the notification must address the number of patients the hospice has been unable to admit because of the shortage, evidence that the hospice has made a good faith effort to hire and retain nurses, a training program in hospice and palliative care for the contracted staff, evidence that the contracted staff is providing care consistent with the hospice’s policy and the patient’s care plan, contracted nurses are supplementing regular hospice staff, and the hospice is continuing recruitment efforts to hire nurses. See the link below for details. (CMS, 9/17, www.cms.gov/Surveycertificationgeninfo/downloads/SCLetter10_31.pdf)

OTHER NOTES

* Dr. Bruce Wilson, president of Milwaukee’s Wilson Heart Care Associates, recently coordinated a CME conference on end-of-life issues. The presenters were lay people who had personal or family experience with end-of-life issues. Wilson said, “In one way or another, all of the speakers held up a mirror to the doctors in the audience and gently asked us to do better. It is safe to say that each one of them touched us deeply.” Wilson adds that “too many patients and far too many doctors don’t understand hospice and palliative care. … In most European countries, doctors in training are required to have 200 to 300 hours of training in end-of-life care. There is no such requirement in most medical schools in the United States.” (The Journal Sentinel, 9/25, www.jsonline.com/news/opinion/103755239.html)

* The natural burial movement is “gaining ground.” Final Footprint (www.finalfootprint.com), which features “environmentally friendly, hand-crafted fair trade caskets and urns,” will have a booth at this year’s Solfest XIV (www.solfest.org). Final
Footprint’s Jane Hillhouse, who has been working for more than 15 years to change funeral industry practices, will make a presentation. **Terry Ward, a land conservationist in Houston, will lead “an evening of multi-cultural, ecumenical dialogue about natural burial and the spiritual and practical importance of planning your own funeral.”** Ward’s series of videos on natural burial can be seen at [www.youtube.com/watch?v=JPqmxE576Bw](http://www.youtube.com/watch?v=JPqmxE576Bw). ([The Huffington Post](http://www.huffingtonpost.com/anne-dilenschneider/natural-burial-is-gaining_b_737516.html), 9/24, [www.huffingtonpost.com/anne-dilenschneider/natural-burial-is-gaining_b_737516.html](http://www.huffingtonpost.com/anne-dilenschneider/natural-burial-is-gaining_b_737516.html))

Thanks to Don Pendley for contributions.

**Glatfelter Insurance Group** is the national sponsor of Hospice News Network for 2010. Glatfelter Insurance Group provides property and liability insurance for hospices and home healthcare agencies through their Hospice and Community Care Insurance Services division. Ask your insurance agent to visit their website at [www.hccis.com](http://www.hccis.com).

**Hospice News Network** is published 45-47 times a year by a consortium of state hospice organizations. Copyright, 2010. All rights reserved to HNN subscribers, who may distribute HNN, in whole or part, to provider members of the subscribers’ state organizations. If readers need further information, they should consult the original source or call their state association office. HNN disclaims all liability for validity of the information. The information in HNN is compiled from numerous sources and people who access information from HNN should also research original sources. The information in HNN is not exhaustive and HNN makes no warranty as to the reliability, accuracy, timeliness, usefulness or completeness of the information. HNN does not and cannot research the communications and materials shared and is not responsible for the content. If any reader feels that the original source is not accurate, HNN welcomes letters to the editor that may be shared with HNN readers. The views and opinions expressed by HNN articles and notes are not intended to and do not necessarily reflect views and opinions of HNN, the editor, or contributors. Only subscribing state hospice organizations have rights to distribute HNN and all subscribers understand and agree to the terms stated here.