
HOSPICE NEWS NETWORK

Recent News on End-of-Life Care

Volume 19, Number 41 November 17, 2015
A Service of State Hospice Organizations

“AID IN DYING” ESTABLISHES BEST PRACTICES

Just as with any other medical intervention, some ways of carrying out Oregon’s “Death with Dignity” law are better than others. In the more than 20 years since the passage of legalization in Oregon, clinicians there have had ample opportunity to develop best practices for physician aid in dying (AID). A recent article published in *The Journal of Palliative Medicine* examines the clinical criteria that have been developed over more than two decades of AID in Oregon.

The gathering and codification of these best practices has been taking place for several years now. In July 2012, “Compassion & Choices convened the Physician Aid-in-Dying Clinical Criteria Committee... to create clinical criteria for physicians who are willing to provide AID to patients who request it.” **The committee, including “experts in medicine, law, bioethics, hospice, nursing, social work, and pharmacy,” used an iterative consensus process as they drafted the criteria over the course of one year.**

The authors of the article detail a variety of these criteria, developed from Oregon physicians’ experience in delivering AID. **They provide best practices in the areas of: responding to requests for AID, ensuring informed consent, providing a prescription, and procedures for life-ending medication.**

Responding to requests for AID: Patients requesting AID must receive a prompt evaluation that explores a holistic range of issues, from the spiritual to the financial. The goals of the physician are: “(1) to deter any premature action by the patient, (2) to establish whether a request reflects decisional capacity and freedom from external pressure, and (3) to ensure that the patient is considering alternatives to AID. It is important that the physician identify patient concerns that could be addressed without AID. AID must reflect a considered and voluntary choice by the patient.” **If there is any question of whether the patient is suffering from a mental health condition, the physician is obliged to refer the patient to a mental health specialist for evaluation.**

Ensuring informed consent: Few patients understand all of their end-of-life options, and it is the physician’s role to ensure that there is full comprehension of all the range of alternatives to AID that exist before prescribing AID. **Options for managing pain and suffering should be fully explored.** In addition, patients should understand that there are options for hastening death that do not involve lethal medication, such as cessation of nutrition and hydration.

Patients should be encouraged to engage in conversations with family members or loved ones about their choice. If this is problematic, the reasons for this should be explored.

Physicians should carefully document the reasons for providing AID based on the patient's medical record, and should ensure that the patient fully understands the likely consequences of receiving AID. Patients should be made aware that AID must be self-administered. "It is personally, professionally, and legally valuable for the physician to obtain this validation and confirmation," though in certain exceptional circumstances an inability to secure a second opinion should not prevent a patient from receiving AID.

Providing a prescription: Oregon, Washington, and Vermont require a 15-day waiting period between the first request for receiving AID and actually obtaining lethal medication. "When a waiting period is not required by state law, physicians may know the patient well enough to determine without difficulty that the request is voluntary, rational, and enduring. If physicians are uncertain about this, they should schedule a follow-up visit in 10 to 15 days to revisit the request." **Providing some space between the request and allowing the patient to act on it should usually clear up any doubt about the patient's intentions.**

"Once physicians have written a prescription for life-ending medication, they must alert the patient's pharmacist. This allows the pharmacist to decide whether or not to participate and to have the appropriate medication available for pick-up." **The authors note that many patients never actually use the lethal medication, eventually dying from the natural progression of their disease.** Having the medication on hand, however, may provide a psychological benefit. "These and other AID patients realize an improvement in their quality of life from the sense of control that comes with mere receipt (not ingestion) of the prescription."

Procedures for life-ending medication: The authors describe the basic procedure for carrying out AID. **The medication protocol is two-step.** "First, the patient takes an antiemetic (e.g., metoclopramide or ondansetron). Forty-five to sixty minutes later, the patient ingests 9 g of a short-acting barbiturate (e.g., secobarbital or pentobarbital)." The authors note that some patients may wish their doctor to be present at the time of ingestion, though this is a personal matter between doctor and patient.

The authors encourage the presence of loved ones, in order to provide comfort and presence to the dying. **"Indeed, a gathering of family and friends can be a rich experience for all."** In order to preserve the confidentiality of patients, physicians in Oregon and Washington list the cause of death as either "respiratory failure" or the patients underlying illness as the cause of death. **The manner of death is listed as "natural," similar to cases when a ventilator is removed.**

AID has only been legal since 1997, and even then only in a few states. Yet the experience gained so far "permits the drafting of clinical criteria to guide physicians when their patients request AID. For physicians who are willing to provide AID, it is important that they be medically knowledgeable doing so. These criteria are designed to provide that knowledge and guidance."

The "Clinical Criteria for Physician Aid in Dying," as well as a complete list of those who served together on the committee doing this work, are available online. (*JPM, online 11/5,*

online.liebertpub.com/doi/abs/10.1089/jpm.2015.0092; *JPM, Clinical Criteria for Physician Aid in Dying*,
http://online.liebertpub.com/doi/suppl/10.1089/jpm.2015.0092/suppl_file/Supp_Data.pdf)

HOSPITAL SURVEYS OFTEN DON'T ASK THE RIGHT QUESTIONS OF END-OF-LIFE PATIENTS

Patient-experience surveys often miss the issues that are most important to terminally ill patients. Writing for *The New York Times*, David Casarett speaks about his experience as a clinician in the VA health system, and the ways that national patient satisfaction surveys could best assess the needs and experience of patients at the end of life. Casarett is director of hospice and palliative care at Penn Medicine.

What are the most important quality factors to consider when selecting a hospital? The kinds of factors surveyed in questionnaires that are given to recent patients of the Veterans Administration, as well as many other hospitals, include questions on a number of issues. They ask about the quality of the food in the cafeteria, the parking accommodations, and the cleanliness of the room. **For many patients, including patients facing terminal illness, the most important questions have been left off entirely.**

Casarett tells the story of “Roy”, whose wife “Sheila” had recently been discharged from the hospital with a diagnosis of terminal breast cancer. Roy had called Casarett to share his consternation that the exit questionnaire had all sorts of questions about accommodations and amenities at the hospital, but virtually nothing about the kind of care that he and his wife would have liked to receive during their time in the hospital.

“These questions didn’t reflect what was important to a 73-year-old woman with incurable breast cancer who knows she’s going to die in the next six months. And they didn’t assess how well we were supporting her husband, who was overwhelmed with being a caregiver and advocate, a father and grandfather. **We asked for their opinions, but we didn’t ask the right questions.**”

This is a significant oversight. Hospitals are increasingly looking to patient surveys like these to evaluate their effectiveness, see how they can improve, and even see how they stack up compared to other hospitals in the national ranking. “These results are also being tied to financial incentives, so hospitals get paid more, or less, by Medicare or insurance companies, depending on what their patients say about them.” **If the concerns of end-of-life patients are not reflected in these surveys, it’s unlikely that they’ll be reflected in future improvements to the nation’s hospital systems.**

Much of this end-of-life feedback may in fact be positive, affirming the efforts that hospitals like those in the VA system are undertaking for terminally ill patients. “Roy and Sheila wanted to tell us about the adequacy of the information they received from our doctors about Sheila’s prognosis and treatment options. And they wanted to compliment the emotional and spiritual support they received from our staff. Most important, Roy said, they wanted to thank the palliative care team, which was especially helpful. **But the survey they received**

didn't give them a chance to share any of those opinions."

We need to be asking questions that address the experience of all patients, especially those facing the most challenging outcomes. Casarett sees no reason why this couldn't start now, nationwide. "National surveys could easily be modified to include questions that are important to patients like Sheila. We could include questions about emotional and spiritual support, control over decisions, adequacy of information and respect for dignity. Those sorts of questions are arguably important for all of us, but they're particularly relevant to those who are facing advanced, incurable illnesses.

Casarett has even developed a solution that can speak to the needs of patients and families at the end of life. Several years ago, he and his colleagues developed a new survey that speaks directly to the experience of dying patients and their loved ones, called the "Bereaved Family Survey." This questionnaire "is sent to families of patients after the patients have died, and asks exactly the sorts of questions — about pain, information, decision making, and emotional and spiritual support — that Roy wanted someone to ask him."

The answers we find in response to these questions may surprise us. Some hospitals may find they are performing far better than they would have guessed, while others could learn that they have not progressed as far as they imagined. But whatever the results, the "Bereaved Family Survey" is allowing Casarett and his colleagues to improve the care that terminally ill patients receive in the VA System. "Families were more satisfied with their care when a palliative care consult team saw the patient," he and his team discovered. "And that they were most satisfied when the patient died in a specialized palliative care unit."

As the VA system begins to benefit from this valuable survey, Casarett hopes that hospitals throughout the United States will begin implementing this tool. He also believes that the results from these surveys should be publicly reported, so that potential patients can make informed decisions about where they want to receive care at the end of life. "If you have a serious, life-threatening illness, you'd want to be cared for in a hospital that offered the best chance of recovery and survival. But you'd also want to know that along the way, your symptoms would be controlled, and you'd have the information and support you needed to make decisions about your treatment. And at the end of life, your preferences for treatment would be honored, and you'd be comfortable and treated with respect." (*The New York Times*, 11/11, opinionator.blogs.nytimes.com/2015/11/11/lessons-in-end-of-life-care-from-the-v-a/; *The Bereaved Family Survey*, http://www.cherp.research.va.gov/PROMISE/ENG_MALE_2013_Survey_Bereavement_Veterans_Affair_HR_May3.pdf)

HOSPICE NOTES

*** *The Journal of the American Geriatrics Society* published a study of medications used by hospice patients in nearly 700 hospices in 2007.** The average number of medications taken by patients 65 and older with cancer, dementia, debility, heart disease and lung disease was 10.2. The study concludes by saying, "People continue to receive disease-focused therapies at the end of life rather than therapies exclusively for palliation of symptoms, suggesting that treatments

may vary according to the person's primary diagnosis." (*Journal of the American Geriatrics Society*, 11/4, onlinelibrary.wiley.com/doi/10.1111/jgs.13795/abstract)

* **Joey Feek of the husband and wife country duo Joey & Rory is receiving hospice care.** Rory reports that she's content with where she is – and where she's going. "The singer, 40, who first revealed she had been battling cervical cancer in June of last year, had announced she was no longer undergoing treatment to fight the disease just last month." (*People*, 11/9, www.people.com/article/joey-feek-hospice-care)

END-OF-LIFE NOTES

* **Medicare's incentive for physicians to have end-of-life conversations with patients is not sufficient to motivate action, says physician Jennifer Brokaw in an article for TIME.** "The proposed level of reimbursement for this complex process is not sufficient to encourage physicians to carry this out properly, nor does it address the perverse incentives of physicians and hospitals to 'do more' even when it is clear that further interventions will not result in extending life with an acceptable quality of life." (*TIME*, 11/10, time.com/4098989/medicare-advance-care-planning/)

* **Racial disparities for end-of-life patients receiving dialysis are real, says a new report.** "African American, Native American, and Asian dialysis patients were 43% to 44% less likely than whites to use hospice before dying." (*EurekAlert*, 11/7, www.eurekalert.org/pub_releases/2015-11/ason-rde102415.php)

* **An "all of the above" approach to end-of-life care leads to more anguish and agony.** "Most medical practitioners argue that surgically inserted feeding tubes for such patients are uncomfortable, alienating and fruitless, requiring restraints and prolonging the course of dying rather than giving the patient more days of a life they would want to live." (*Dallas News*, 11/8, www.dallasnews.com/business/health-care/20151108-default-of-do-it-all-care-at-end-of-life-takes-toll-in-agony-expense--and-its-worse-in-dallas.ece)

* **For long-term care, is it better to be in the hospital, or at home?** "A new guide for long-term care residents and their families explains the risks and benefits of treatment in long-term care versus transfer to the hospital." The guide is titled "Go to the Hospital or Stay Here?" English and Spanish versions are available online. (*McKnight's*, 11/6, www.mcknights.com/guest-columns/a-guide-for-family-members-demanding-hospitalization/article/452250/; *Florida Atlantic University*, <http://nursing.fau.edu/index.php?main=6&nav=979>)

* **US News Health shares the story on the role of children as caregivers for their loved ones.** "About 1.4 million children between ages 8 and 18 are caregivers nationwide, according to the American Association of Caregiving Youth." (*US News Health*, 11/11, health.usnews.com/health-news/patient-advice/articles/2015/11/11/when-kids-are-the-caregivers)

* **Kelly Michelson, associate professor of Pediatrics at Northwestern University tackles the question of how teachers should talk about death in the classroom.** "How do you explain to

hundreds of grade school children that a beloved kindergarten teacher with breast cancer is dying?” Michelson provides resources to support teachers in this work. (*The Washington Post*, 11/13, www.washingtonpost.com/news/answer-sheet/wp/2015/11/13/why-death-should-be-discussed-in-school-and-how-teachers-should-handle-it/)

* ***Rolling Stone* covers the indie film, “James White,” which is about a wayward son finally forced to take responsibility.** “He’s here now, mopping the sweat off his mother’s forehead, carrying her frail body to the bathroom — ‘like a princess,’ he jokes — doing everything he can to make it through the night with her. She’s deep into Stage IV cancer, and he’s finally giving a hard look to that 24-hour hospice number taped to the refrigerator.” (*Rolling Stone*, 11/13, www.rollingstone.com/movies/news/the-art-of-dying-inside-the-devastating-drama-james-white-20151113)

* **Libraries are learning to play host to conversations about the end of life.** Death cafes are becoming regular occurrences at libraries across the United States. (*American Libraries Magazine*, 10/30, americanlibrariesmagazine.org/2015/10/30/when-subject-is-death-library-death-cafes/)

* **NPR tells the story of one family facing a series of wrenching decisions.** Learning that their unborn son faces serious health problems, the Shamiyeh family continually chooses to prioritize their son’s survival. But when is enough enough? (*NPR*, 11/13, www.npr.org/sections/health-shots/2015/11/13/455677565/an-ill-newborn-a-loving-family-and-a-litany-of-wrenching-choices)

OTHER NOTES

* **Authors of a study published in *The Journal of Palliative Medicine* recommend that all hospitals put into place bereavement programs for families of deceased patients.** “Bereavement programs can both help bereaved individuals adapt to their loss, and positively impact hospitals by enhancing the reputation of the hospital within the community and providing an avenue for identifying opportunities for improvement in care processes.” (*JPM*, 10/28, <http://www.ncbi.nlm.nih.gov/pubmed/26275079>)

* **Medical students in Massachusetts are pushing for more pain management training.** “We want to be a generation of physicians that can tackle the opioid crisis head-on,” said Harvard Medical School’s Helen Jack. (*WWLP*, 11/12, wwlp.com/2015/11/12/mass-medical-students-push-for-more-pain-management-training/)

* **Most Arizona residents say they want to have the option to end their own lives if they become terminally ill.** A recent poll conducted in Arizona indicates that 63% of individuals over the age of 55 support the adoption of an Oregon-style law allowing physician-assisted suicide. (*Yuma Sun*, 11/9, www.yumasun.com/news/poll-most-arizonans-seek-ability-to-end-their-lives-if/article_37eaf092-8746-11e5-b04d-3f6776c9876c.html)

* **The US Senate has approved a bill that would give veterans access to medical marijuana.** “The Senate passed the FY2016 Military Construction and Veterans Affairs (MilCon-VA)

Appropriations Bill, which includes language to allow Veterans Administration (VA) doctors to recommend medical marijuana to their patients in states where medical marijuana is legal. The language was included as an amendment in the Senate Appropriations committee in May.” (*Drug Policy Alliance*, 11/10, www.drugpolicy.org/news/2015/11/senate-approves-funding-bill-allows-veterans-access-medical-marijuana)

*** “New draft guidelines from the Centers for Disease Control and Prevention (CDC) aimed at reducing opioid abuse and addiction have triggered a backlash from pain management experts, many of whom see the guidelines as being nothing short of misguided.”** The CDC has been “criticized for a perception of secrecy and collusion with special interests...” (*Pain Medicine News*, 11/2015, www.painmedicineneeds.com/ViewArticle.aspx?ses=ogst&d=Policy+&+Management&d_id=83&i=November+2015&i_id=1244&a_id=34181)

Thanks to Don Pendley and Faith Kelley for contributions.

Hospice News Network is published 45-47 times a year by a consortium of state hospice organizations. *Copyright, 2015. 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 exists to provide summaries of local, state and national news coverage of issues that are of interest to hospice leaders. 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.