HOSPICE NEWS NETWORK

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

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NHPCO ISSUES POSITION STATEMENT ON PALLIATIVE SEDATION FOR IMMINENTLY DYING PATIENTS

NHPCO has just issued its position paper on palliative sedation, "National Hospice and Palliative Care Organization (NHPCO) Position Statement and Commentary on the Use of Palliative Sedation in Imminently Dying Terminally III Patients." Available from the website of the *Journal of Pain and Symptom Management* at the link below, the paper was written by Timothy W. Kirk, PhD, and Margaret M. Mahon, PhD, RN, FAAN, for the Palliative Sedation Task Force of NHPCO's Ethics Committee.

The paper defines palliative sedation as "the lowering of patient consciousness using medications for the express purpose of limiting patient awareness of suffering that is *intractable* and *intolerable*." NHPCO says that it should be considered "for the limited number of *imminently dying* patients who have pain and suffering that is (a) unresponsive to other palliative interventions less suppressive of consciousness and (b) intolerable to the patient."

The statement addresses availability of terminal sedation for the patients defined above, proportionality (titration of the medication to the minimum level needed to relieve suffering), and the need for interdisciplinary evaluation, ongoing education for all involved in administering it, and the distinction between palliative sedation and assisted suicide. The Ethics Committee was unable to reach a consensus on the use of palliative sedation for existential suffering. NHPCO therefore "strongly urges providers to carefully consider this question and supports further ethical discussion. NHPCO also encourages research within and across disciplines to build an evidence base supporting multiple interventions for existential suffering."

The commentary carefully defines all the terms used in the position statement and discusses each point. It also examines the indications for palliative sedation, and the issues which should be discussed before initiating it – concurrent life-sustaining therapies, artificial nutrition and hydration, the proximity to death, and the level of sedation.

NHPCO recommends regularly reviewing the use of palliative sedation, which should be a formal process. It also recommends "developing and implementing a written institutional policy addressing 1) the criteria and procedure for administrating palliative sedation, 2) the concomitant use of life-sustaining therapies, 3) ongoing education regarding evolving clinical evidence and best practices as well as important ethical distinctions between sedation and assisted suicide or euthanasia, and 4) careful monitoring and collection of data

related to institutional practices of palliative sedation." (Journal of Pain and Symptom Management Website, <u>www.jpsmjournal.com</u>)

DARTMOUTH ATLAS LAUNCHES NEW WEBSITE

The new website of the Dartmouth Atlas of Health Care Project (link below) says that for 20 years, the Project has "documented glaring variations in how medical resources are distributed and used in the United States. The project uses Medicare data to provide information and analysis about national, regional, and local markets, as well as hospitals and their affiliated physicians."

The new site has custom maps, grids, trend reports, charts and fact sheets, databases which allow maps, charts and tables to be created and downloaded for presentations, and search capabilities to compare entities such as states, hospitals, primary care service areas, etc. Additionally, a "key issues" section provides information on "Medicare spending, supply-sensitive care, preference-sensitive care, the physician workforce, end-of-life care, racial disparities, accountable care organizations and more." Fourteen years of archived media coverage is also included.

Downloadable files include crosswalk files defined by zip code, geographic boundary files, hospital performance reports by state and system, Medicare mortality rates, surgical and medical discharge rates, measures of inpatient utilization in the last six months of life, Medicare reimbursement measures, and hospital and physician capacity measures. (*Dartmouth Atlas of Health Care Website*, www.dartmouthatlas.org; *Medical Futility Blog*, 4/22, medicalfutility.blogspot.com/2010/04/dartmouth-atlas-project-launches-new.html)

PAIN & MEDICAL MARIJUANA NOTES

* NeurogesX, a small pharmaceutical company, is marketing a pain-relieving skin patch that produces effects that last three months. The FDA approved Qutenza late last year, and it is also being marketed in Europe and Hong Kong. One analyst says it "could be widely adopted as a treatment for chronic peripheral neuropathic pain conditions." (*Daily Finance*, 4/23, www.dailyfinance.com/story/investing/inside-wall-street-this-little-pharma-may-have-a-big-pain-relie/19450597/)

* "Medical Marijuana and the Law," in the current *NEJM*, reviews the laws of the states that have legalized medical marijuana, and discusses the issues raised by the patchwork of statutes. Allowable amounts of marijuana vary widely. Some states protect patients with identification cards from being arrested while others do not. Most do not require physicians to disclose the risks and benefits needed for informed consent. The authors say that the state laws are a "political response" to patients needing pain relief, but "are inadequate to advance effective treatment." They encourage reclassification of marijuana as a Schedule II drug "to facilitate rigorous scientific evaluation of the potential therapeutic benefits of cannabinoids and to determine the optimal dose and delivery route for conditions in which efficacy is established" Federal laws, and regulation by the FDA, would remove patients and physicians from their current "precarious legal position." (*NEJM*, 2010;362:1453-1457, content.nejm.org/cgi/content/full/362/16/1453)

* With medical marijuana legal in 14 states, employers are "struggling to reconcile zerotolerance drug policies with a patient's right to get high. Human resources managers are grappling with such questions as whether random drug tests constitute discrimination under the Americans with Disabilities Act, what they are legally allowed to ask job candidates and whether they are required to accommodate after-hours and offsite use of medical marijuana." (USA Today, 4/20, www.usatoday.com/money/industries/health/2010-04-20-medical-marijuana-side_N.htm)

* The editorial board of the *Idaho Press-Tribune* could not come to a conclusion on whether medical marijuana should be legalized, so "presented the best arguments on both sides." The editorial came in response to Representative Tom Trail's (R) proposal to legalize it for seriously ill patients. (*Idaho Press-Tribune*, 4/22, www.idahopress.com/opinion/editorial/article_33f3f42e-4da0-11df-964d-001cc4c002e0.html)

PUBLIC POLICY NOTES

* On April 21, Hospice Advocates from across the country took part in NHPCO's Capitol Hill Day, meeting with elected representatives and "encouraging policy makers to preserve and protect access to compassionate, high-quality end-of-life care for all Americans." Thousands of others participated online, making phone calls and emailing their representatives. Hill Day and Virtual Hill Day emphasize the value of hospice to communities and remind Congress of the "unique structure" of the Medicare Hospice Benefit. (*NHPCO Press Release*, 4/21, www.nhpco.org/i4a/pages/index.cfm?pageID=5855)

* Recent news reports indicate that Donald Berwick, currently nominated as CMS administrator, will face questions from senators on his end-of-life views. Some Republican senators reportedly are also concerned that Berwick will "ration" healthcare. (*McKnight's Long Term Care News*, 4/22, <u>www.mcknights.com/cms-nominee-berwick-may-face-questions-on-healthcare-rationing-during-confirmation-hearings/article/168509/</u>

* A former Minnesota nurse has been charged with two felony counts of aiding suicide for helping a British man and a Canadian woman commit suicide. According to the article, William Melchert-Dinkel "told police he went on the Internet and encouraged dozens of depressed people to kill themselves for the 'thrill of the chase." The Minnesota Board of Nursing revoked Melchert-Dinkel's license after he was "cited several times for neglect and being rough with patients." (*The Washington Post*, 4/23)

HOSPICE & PALLIATIVE CARE NOTES

* In Paducah, Kentucky, Western Baptist Hospital has a new palliative care program. D. Preston Figge, MD, is a chaplain at the hospital, and helped organize the program. Dr. Figge published an article in the *Journal of Pastoral Care and Counseling* about the care of a patient with advanced cancer who was estranged from his family. Figge says that the care he received shows that underneath a large health system lies "a flowing stream of compassion ... that recognizes the value of each individual's need to be loved and respected at the end of life." Figge's article is posted on Western Baptist's website at

www.westernbaptist.com/Patients+%26+Visitors/A+Case+Presentation+Becomes+a+Morning+

<u>Meditation</u>. The article about the program is in the link below. (*Senior Home Care Information*, 4/24, www.seniorhomecareinformation.com/hospice-care/western-baptist-offers-palliative-care-for-life-limiting-illnesses/)

* Ten years ago Jacksonville's Community Hospice hired a social worker and a nurse and sent them to go "hang out" at Wolfson Children's Hospital. For two years, the two helped hospital staff deal with dying youngsters, and asked both providers and families what they needed. **Out of that effort came Community Pedscare**, which deliberately omitted the word "hospice" from its name. Pedscare now averages 100 patients at a time, and only 5%-10% are hospice patients. The others have chronic diseases or special needs that require a lot of care. (*Florida Times-Union*, 4/17, jacksonville.com/news/metro/2010-04-16/story/childrens-hospice-program-lives-softening-deaths-blow)

* In Pennsylvania, a group of Hospice of Lancaster County staff has received accreditation from the National Institute for Jewish Hospice, as well as special training in providing services to members of the local Jewish community. Though there are few Jewish people in the area, local rabbis encouraged the Hospice to create a team of people who understood their needs. (*Lancaster Online Website*, 4/23, articles.lancasteronline.com/local/4/251717)

* Oklahoma's Hospice of Green Country established the Pet Peace of Mind Program to provide for patients' pets when they are unable, physically or financially, to care for them. Pet Peace of Mind, which has its own website at <u>www.petpom.com</u> and a blog at <u>petpeace.blogspot.com/</u>, accepts donations from individuals, but looks for other sources of funding as well. It is currently trying to win a \$250,000 grant from Pepsi by asking people to vote in Pepsi's online poll at <u>www.refresheverything.com/helphospicepatientskeeptheirpets</u>. (*Hospice of Green Country Website*, <u>www.hospiceofgreencountry.org/hospice/Pet_Peace_of_Mind_EN.asp</u>)

OTHER NOTES

* An article in *The Shreveport Times* encourages people to discuss end-of-life preferences. The author interviewed Damiano de Sano Iocovozzi, a nurse practitioner who has worked with terminally ill patients for 23 years, and who recently published *Sooner or Later: Restoring Sanity to Your End-of-Life Care.* The interviewer says, "I promise you that this interview and this book will make you think. It's not going to feed you any answers, because that's for each of us to decide individually and with our families, but it will give you current and accurate information so that you can make wise choices. At the very least, let's begin a conversation that can pay rich dividends for each of us, sooner or later." The interview can be heard at www.strategiesforliving.com – look under "Featured Podcasts." (*The Shreveport Times*, 4/19, www.shreveporttimes.com/article/20100419/LIVING0408/4190309/End-of-life-decisions-difficult-but-important)

* In Morganton, North Carolina, Ron LaSalle is president and CEO of Burke Hospice & Palliative Care. He also has terminal esophageal cancer. He tried chemotherapy, but the cancer spread, and LaSalle elected to "look at unproven therapies that might have potential for benefits." According to the article, "Because he already faces possible death, LaSalle said he isn't afraid to try unproven treatment methods that may help researchers studying these different methods. And that's part of the reason why he keeps meticulous notes and records his treatment techniques. 'T'm willing to be a guinea pig. I'm willing to try anything," LaSalle said." His blog is a

www.ronsvictory.com. (The News Herald, 4/25, www2.morganton.com/content/2010/apr/18/lasalle-battles-cancer-alternative-treatments/)

* Researchers believe that psychedelic drugs could be used to relieve anxiety, and may someday be used to treat cancer anxiety and post-traumatic stress disorder. Rick Doblin, of the Multidisciplinary Association for Psychedelic Studies, says, "There is now more psychedelic research taking place in the world than at any time in the last 40 years." But Doblin says that raising money for research isn't easy, with "government funders still leery and drug companies not interested in the compounds they can't patent." (*The New York Times*, 4/23, www.nytimes.com/aponline/2010/04/23/health/AP-US-MED-Psychedelic-Therapy.html)

* Spirituality, Health, and Healing: An Integrative Approach (Second Edition), by Caroline Young and Cyndie Koopsen, is now available in bookstores. The product description says that this book "offers health care professionals and individual caregivers the guidelines and tools necessary to provide compassionate, spiritual care to their clients and patients. By describing the profound role of spirituality on the body, mind, and spirit, this resource is an essential asset to practitioners eager to enhance their understanding of this important topic." (Daily Break News, 4/25, dailybreaknews.com/spirituality-health-and-healing-an-integrative-approach-second-edition/512; Amazon Website)

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