



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

### **December 16, 2019**

#### **A Service of Your State Association**

### **MEDPAC PRESENTATION CALLS FOR NO HOSPICE RATE INCREASES AND REDUCTION IN AGGREGATE CAP**

The Medicare Payment Advisory Commission (MedPAC) held its public meeting on December 5-6, 2019. MedPAC makes recommendations to Congress each year on the adequacy of hospice (and other provider) payments, and on action the Congress should consider.

In the December 6, 2019, meeting, Kim Neuman, a principal policy analyst for MedPAC, offered a presentation on hospice to MedPAC commissioners. MedPAC staff reported that their research finds “that access to care is trending upward, while quality seems to have improved slightly. Hospices also have steady access to capital and robust Medicare margins—12.6% overall—so there's little reason to worry that beneficiaries' access to care would be hurt by financial problems anytime soon.” And, said Neuman, “The hospice rates may be higher than needed to ensure appropriate access to care.” She also shared that longer stays by patients lead to higher margins for hospices.

MedPAC “will likely recommend to Congress that they shouldn’t increase the conversion factor, or base payment amount, for hospices.” This would mean that hospices receive no updates in payment rates for 2021. MedPAC will also likely recommend to Congress that they act to “wage adjust and reduce the hospice aggregate cap by 20 percent.” The recommendations will be voted on at MedPAC’s meeting in January, 2020.

An article in *Modern Healthcare* offered summary notes on the meeting. Hospice providers opposed the recommendations that were proposed by MedPAC. Edo Banach, NHPCO, expressed that NHPCO does not agree with the move to reduce the hospice cap. To do so, said Banach, makes decreases in hospice access more likely. Instead, NHPCO urged, MedPAC should “use a targeted approach that will have a higher likelihood of rewarding high quality, punishing low quality, and increasing access.”

MedPAC believes, says the article, that “lowering the aggregate cap and wage adjustment would help level the playing field for hospice providers, generate cost savings and target the most profitable hospices with payment cuts.” MedPAC also projects that the changes will mainly impact free-standing and for-profit hospices. This is “because their average lengths of stay are much higher.” James Mathews, executive director of MedPAC shared, “Some larger hospice organizations track how close they are to the aggregate cap and their average length of stay” And, says Mathews, “They even adjust their business practices to make sure they don't exceed the limits.”

There was some sharing and lamenting by MedPAC members about how much hospice care has changed since the early 1980's. The Medicare benefit has not changed much, while patient needs and medical practices have been transformed.

The report, which is available online at the second link below, provides a background on how hospice payments work; an overview of Medicare hospice utilization; an examination of the adequacy of payments to hospice providers of care; data on the growth of for-profit hospices; and, data on hospice utilization and quality of care—noting that quality data are limited. Access to capital remains strong-or appears to do so, says the report. Margins for providers varies by provider types, and the report provides data on these types of providers. Hospice margins, says the report, increase according to the length of patient stays. Overall, the report says, hospice “payment adequacy is generally positive. (MedPAC Meeting Brief) [Read the MedPAC brief here.](#) (MedPAC, CMS Meeting Presentation, December 6) [Read more...](#) (Modern Healthcare, 12/6) [Read more...](#)

### **JPM ARTICLE SAYS DO-NOT-OPERATE ORDERS SHOULD BE ADDED TO MEDICAL ORDER FORMS**

A do-not-operate (DNO) section should be added to medical orders for life-sustaining treatment (MOLST) and physician orders for life-sustaining treatment (POLST) forms, says an article in this month's *Journal of Palliative Medicine (JPM)*. The article, written by a group of authors, calls for modifications to the forms. The goal in adding the DNO section to the existing do-not-resuscitate (DNR) and do-not-intubate (DNI) sections would be to “[reduce] suffering from nonbeneficial surgical interventions in patients with severe illness at the end of life,” they say.

“Advanced care planning has been found to decrease patient anxiety as well as improve satisfaction of surviving family members with the quality of end-of-life care provided,” the authors say. The MOLST and POLST forms have proven to be excellent tools in clearly and simply indicating patients' wishes for life-sustaining interventions before reaching emergent situations where decisions may need to be made. However, there is currently no space on the forms for indicating patients' preferences regarding operative interventions. “Unfortunately, the need for operative intervention often arises emergently, when patients may not be lucid or family members either unavailable or unsure as to how to proceed,” the authors say.

When it comes to improving quality of life for terminal patients, operative interventions are important to examine. “An evaluation of quality of life outcomes in cancer patients nearing the end of life revealed a negative association between the number of aggressive interventions and quality of life,” they explain. Further, additional suffering can be caused by surgical interventions. “In a recent study examining outcomes after emergency abdominal surgery in patients with advanced cancer, 67% of patients who underwent surgery for perforation had complications and 52% were discharged to acute and subacute rehabilitation centers and long-term acute care centers,” they point out. Another study that examined results of operations done with a palliative intent showed that 80% of operations did result in an improvement of symptoms. However, 29% of operations in the study resulted in complications. When complications occurred, symptom improvement was only seen at a rate of 17%.

DNO orders can be complicated and imperfect, the article notes. The settings in which the decision to operate can come up are varied in urgency and purpose. The definition of “operation” can be loose, as well. “However, these limitations may be offset by allowing orders to be omitted, suspended, or reversed at any time, and with an ability to incorporate ‘partial’ DNO orders,” they explain. What it comes down to is that good communication and expectation-setting is key. This should include discussion of “(1) the underlying disease process, (2) anticipated acute medical problems, (3) prognosis, and (4) overall goals and values in the context of meaningful outcomes, such as symptom alleviation.”

“Goal-oriented shared decision making should be performed to determine a patient's wishes regarding resuscitation, intubation, and operations at the end of life,” the authors conclude. (*Journal of Palliative Medicine*, 11/12) [Read more...](#)

## TWO OPPOSING PERSPECTIVES ON PAIN TREATMENT

James D. Hudson, medical director of Mary Free Bed Pain Rehabilitation Program in Grand Rapids, Michigan, says that Americans’ attitude toward pain and pain management has gone awry and led to the opioid crisis. His opinion piece in *The Washington Post* he says, “Life isn’t ‘pain free.’ If we want to end the epidemic of addiction, we need to relearn that lesson.” Indeed, the subtitle to his *Post* article is, “We used to know how to manage discomfort. Our quest to banish it brought on the opioid crisis.”

Hudson says that when he was a medical student 40 years ago, he learned that pain was an important diagnostic tool. Today, he says we have collectively developed a “dangerous fear of pain.” This shift, he says, was prompted by changes in the field in the 1990s, ushered in by the actions of Dr. Jack Kevorkian, and pharmaceutical companies “aggressively marketing” opioids. He notes that the American Pain Society reframed pain as “a vital sign and an illness in its own right, instead of a symptom of an injury or an underlying condition.” As a result, he says “Many doctors listened to the marketing campaign. In our hubris, we began to think we had the capacity to banish chronic pain.”

He blames this “opioid revolution” for leading us to the opioid crisis. As for actions that resulted in the crisis, he cites drugmakers placing no upper limits on opioid dosages, and what he implies to be a willful ignoring of the threats of addiction. Further, he says that practitioners create a fear of pain in their patients. Insurance companies are complicit too, he says. “They reimburse interventional pain treatment so handsomely that these practitioners have become some of the highest-paid specialists in the country.”

Hudson says this treatment of pain isn’t working, though. Chronic pain patients find that targeted treatment results in the pain being experienced elsewhere. We need a new approach to managing pain, he says. “New approaches hope to teach self-management by educating patients about their bodies and nervous systems, reducing fear of pain, and treating depression and hopelessness — partly by getting them back to exercise and normal activities...Patients learn how the thoughts they have, the words they use and the beliefs that underlie them can either increase or decrease their nervous system’s danger signals.” He likens living with chronic pain to living next to the disruptively loud El train in Chicago. “You get used to it. Getting angry every time a train passes is a sure way to obsess over it. Our body’s pain system works the same way. The more we learn to calm it down, the less it bothers us; the more we try to be pain free, the more it takes over our lives.”

Jeffrey A. Singer, general surgeon, Senior Fellow at the CATO Institute, and a voice for the harmful effects of drug prohibition, doesn’t agree with this analogy, or many of Hudson’s other views. In a blog post in the *CATO Institute Blog*, and a letter to the editor published by *The Washington Post*, Singer outlines the concerns he has about Hudson’s article. He dismisses Hudson’s case against the opioid crisis, calling public policy toward this issue “panic-driven,” lacking in evidence, and incited by the media. “As doctors are pressured by law enforcement and policymakers to curtail the treatment of pain, it seems a market has developed for articles by pain management doctors urging patients to ‘suck it up’ and learn to live with pain,” Singer says, suggesting Hudson “responded to the market demand.”

What Hudson and the media fail to acknowledge, Singer says, is that the vast majority of overdoses are the result of black-market drugs like heroin and illegally obtained fentanyl. These victims of drug-use are almost never pain patients. “Unfortunately, this return to a pre-modern approach to pain management will do nothing to stop the overdose rate, on a steady exponential increase since at least the late 1970s—well before the creation of OxyContin,” Singer says. In addition to Singer’s feedback on the article, 1400+ readers have responded online to Hudson’s article. (*The Washington Post*, 11/27) [Read more...](#) (*The Washington Post*, Letters to the editor, 12/4) [Read more...](#) (CATO Institute Blog, 12/4) [Read more...](#)

## HOSPICE END-OF-LIFE NOTES

\* On December 1, CMS published measures they are considering. The measurements under consideration (MUC) include a proposed measure for “Hospice Visits in the Last Days of Life.” The measure will assess visits to patients or caregivers, looking for at least two visits from registered nurses or social workers during the last three days of the patients’ life. The hospice claims records will be used for the measurement, which will replace the current “Hospice Visits When Death Is Imminent” measure. (*CMS’s List of Measurements that are Under Consideration for December 1, 2019*) [Learn more...](#)

\* The Episode 5 podcast of the *Hospice and Palliative Nurses Association’s (HPNA) Podcast Corner* is available for listening on their website. The episode is entitled “Stories from the Field with Dr. Kristopher Halsey.” Guest Dr. Kris Halsey draws from his 20 years as a clinical chaplain to tell stories of rewarding spiritual experiences and challenges in supporting patients at the end of their lives and their loved ones. “His passion to see lives change is inspiring in its message of compassion: compassion for our patients, our families, each other as professionals, and ourselves,” *HPNA Podcast Corner* says. (*Hospice and Palliative Nurses Association’s Podcast Corner*, 12/6) [Access the podcast here.](#)

\* Writer Alisa Schindler writes a personal essay in *The Washington Post* about how difficult it can be when a loved one’s physician gives false hope at the end-of-life. Schindler describes how her father’s doctor never gave any indication that he was dying during his struggle with cancer. Instead, in their visits with his doctor, the physician would say encouraging things like, “Your numbers look great,” and “Everything looks good.” Months after her father’s death, Schindler’s father-in-law was also diagnosed with cancer. His doctor made similarly hopeful remarks. Schindler describes his death as “traumatizing” because they were led to believe he could get better. The conversation around dying needs to be changed, Schindler concludes. “Maybe I’m wrong in thinking the doctors should have given warning, although the few doctors I have since spoken with all have said that it’s better to have the conversation, however difficult,” she says. “Had I known death was so near, I could have been more prepared and more gentle, but I wasn’t, and now I have to live with that.” (*The Washington Post*, 11/24) [Read more...](#)

\* Episode 222 of the *End of Life University* podcast, “The Benefits of Medical Hypnosis at the End of Life, with Roger Moore,” is available for listening at their website. Guest Roger Moore works with patients at the end of their lives and their caregivers as a medical hypnotherapist. In the episode, he discusses medical hypnosis and what a typical session looks like, the benefits of hypnosis, how it helps with fears of death and dying, specific techniques like the “wiggle” and “flow through” techniques which can help patients through suffering, how hypnosis can help reduce needs for pain medication, and many other topics. (*End of Life University*, 11/25) [Access the podcast here.](#)

\* *The Columbus Dispatch* writes about death doulas, including local professional death doula, Donna Baker. Baker supported local weatherman and close friend, Chris Bradley, at the end of his life. Baker kept Bradley company, anticipated his needs, and helped with personal tasks such as writing a love letter to his surviving husband, Jason Bradley-Krauss. It was Bradley who encouraged Baker to pursue a career as a death doula. President of the International End of Life Doula Association (INELDA), Janie Rakow, explains the role of death doulas: “We journey with the person who’s dying and their family to help them navigate through the whole end-of-life process.” Rakow says many hospices work with doulas, but the response has been mixed. Baker also cites supporting her father during the end of his life as providing inspiration toward her work as a death doula. She quit her job in advertising to pursue training at INELDA before eventually starting a private practice. “Donna helped me talk through things and talk about a lot of my fears, and I know she was amazing at talking to Chris and helping him arrive at a place of great peace,” Bradley-Krauss says of Baker’s support. “I saw such benefit in having those important conversations ... Because nothing was left unsaid, the healing process for me has been easier.” (*The Columbus Dispatch*, 12/3) [Read more...](#)

## PALLIATIVE CARE NOTES

\* *Chattanooga Times Free Press* tells the story of local man, Mike Ward, to illustrate how palliative care is not just for the dying. Ward began having health troubles while in his late 30s when he was diagnosed with Crohn’s disease. He also developed blood clots and had his first of several heart attacks at the age of 40, despite seeming to be in otherwise good health. Ward has been living thanks to a left ventricular assist device since one such heart attack. He is ineligible for a heart transplant due to liver disease, but the device is buying him time to spend with his family. Since receiving the device, his doctors have had him enrolled in palliative care to help manage symptoms associated with his condition. Mary Danielson, spokeswoman at Palliative Care Services where Ward is a patient, says many misconceptions keep patients away. “Those range from the falsehood that palliative care is for dying patients to patients having to give up their doctors to receive palliative care,” Danielson says. “Unfortunately, the myth that patients have to give up their doctors is also prevalent among doctors who think they have to give up their patients. In reality, we co-manage care with their doctors.” Ward is impressed with the level of care he receives from his palliative care team. “They’re not really treating my disease. They’re treating my symptoms,” he says.



“Sometimes that can be having a goal for myself and them helping me to achieve it by encouragement. I’m not gonna get that at my heart doctor. He’s not going to ask me, are you living on your own again? It’s just not his priority, and that’s their priority here.” (Chattanooga Times Free Press, 11/30) [Read more...](#)

\* The Coalition to Transform Advanced Care (C-TAC) writes about BJ Miller’s coverage on NPR’s *Fresh Air*. In his interview with host Terry Gross, Miller discusses how he was inspired to pursue palliative care and medicine after an injury in college resulted in him having both of his legs and one arm amputated. He also discussed “the complexity of suffering,” C-TAC says, “noting that it [suffering] has physical, psychological, emotional and spiritual components,” which Miller says are addressed by palliative care. Miller and co-author Shoshana Berger wrote *A Beginner’s Guide to the End: Practical Advice for Living Life and Facing Death*. Miller has also recently launched a website called Center for Dying and Living. It’s meant as a place for the ill and their caregivers to share stories of “living with illness, disability, or loss,” C-TAC explains. The full interview with Terry Gross can be heard on NPR’s website. (Coalition to Transform Advanced Care, 12/6) [Read more...](#) (NPR, 12/3) [Read more...](#) (Center for Dying and Living) [www.thecenterfordyingandliving.org](http://www.thecenterfordyingandliving.org)

\* A recent study called “Palliative Care and Moral Distress: An Institutional Survey of Critical Care Nurses” indicates that nurses who lack palliative care training experience more moral distress in clinical settings. Further, less than 40% of respondents indicated high competency in any area of palliative care, and 38% said they’d received no palliative care education in the past two years. *Oncology Nursing News* asks the principal investigator and co-author of the study, Kenneth R. White, PhD, RN, ACNP, ACHPN, who is a professor of nursing and palliative care nurse practitioner, about the implications of this study. White discusses palliative care resources for nurses and the work that went into the study. White also underlines the importance of inter-professional collaboration. “It has been shown that when nurses have more knowledge about palliative care, the moral distress *may* increase when their patients are not receiving the best care possible, which may include palliative approaches,” he says. “Palliative care is a discipline that must be learned and practiced inter-professionally.” (Oncology Nursing News, 12/3) [Learn more...](#)

## OTHER NOTES

\* The Oregon POLST Coalition is sharing “Guidelines on POLST Use for Persons with Significant Disabilities who are Now Near the End of Life” in a document available online. The document covers topics such as when POLST should be completed, what to do when the condition of a patient with a POLST form has changed, the role of decision-makers, and the appropriate use of POLST for persons with disabilities. They stress that POLST is not intended for those with stable long-term disabilities who are not near the end of their lives. This appropriate use of POLST is one of the two stated main goals of the document, along with “[promoting] broader access to high quality end of life care for persons with significant disabilities who are nearing the end of life.” Oregon POLST welcomes feedback which could help to make the document a stronger resource. (*Oregon POLST Coalition*, 11/2019) [Read more...](#)

\* *New York Times* shared the story of the life—and death-- of Marieke Vervoort, celebrated Belgian Paralympic gold medalist, who recently died by euthanasia. Vervoort’s fame came in part to her frank discussion of her election to one day die on her own terms, taking advantage of Belgium’s liberal medical aid-in-dying laws. “No country has more liberal laws for doctor-assisted death than Belgium, a country of 11 million people, where 2,357 patients underwent euthanasia in 2018,” *The New York Times* (NYT) says. Vervoort had gotten the authorization to choose euthanasia years earlier – before she competed in the Paralympics. Knowing that she would have control over how and when she died is what gave her the strength and will to go on living through her pain for so long, she said. “Because of those papers, I started to live again,” says Vervoort. NYT explains, “Her days were no longer consumed with dark thoughts of how her life would end. Mentally, she felt free.” Andrew Keh and Lynsey Addario from NYT spent the last three years leading to Vervoort’s death following her and reporting on her life. “Knowing she had the legal right to die helped Marieke Vervoort live her life. It propelled her to medals at the Paralympics,” they say. An interactive piece on the NYT website tells this story with intimate photos and details. (*The New York Times*, 12/5) [Read more...](#)

\* A *Definitive Healthcare* study shows that the home healthcare market is set to expand its offerings but still faces challenges with staffing shortages. This coincides with the aging population, as more and more of the Baby Boomer generation will be needing additional care options. “Over 61% of respondents said staffing is the biggest problem facing their organization, nearly 20% more than the second-place answer: profitability,” *HealthLeaders* says of the study results. To face staffing shortages, 84% of respondents say they anticipate more remote patient-monitoring in the next two years. Nearly three-fourths of respondents also indicate plans to expand specialized services such as palliative care. “More than 70% anticipate utilizing medication management technology and more than 60% plan to have mobile applications for concierge services,” *HealthLeaders* says. (*Definitive Healthcare*, 12/3) [Read more...](#) (*HealthLeaders*, 12/3) [Read more...](#)



\* A new report, entitled *Burning the Candle at Both Ends: Sandwich Generation Caregiving in the U.S.*, comes from a partnership between The National Alliance for Caregiving (NAC) and Caring Across Generations. The report examines the “Sandwich Generation,” or those caregivers who are “sandwiched” between caring for their children and other seriously ill or disabled adult family members. This group comprises more than 11 million Americans, mostly Millennials and Gen-Xers, and are generally younger and more diverse than other caregivers, *ehospice* says. The study examines this group and the challenges they face, such as financial strain reported by 1 in 5 sandwich caregivers; poor workplace benefits, such as little or no paid leave; a weekly average of 22 hours of caregiving, usually on top of employment; and emotional stress and strain reported by one-third of sandwich caregivers. C. Grace Whiting, J.D., President/CEO of the NAC says “Families are squeezed, and they need help to balance work and home life...Now is the time to invest in workplace flexibility and a robust national infrastructure that can support and augment care for the friends and family who need our care.” A live webinar accompanied the release of the report and national briefing. A recording of the event can be viewed on the NAC’s Facebook page. (*ehospice*, 11/27) [Learn more...](#)

\* Writer Suzanne Boles discusses the benefits a meditation practice can have for grief. In her essay at *Next Avenue*, Boles shares how mindfulness meditation helped her in her own grieving process when she lost her husband. Quoting *Verywellmind.com*, Boles explains that mindfulness meditation “is a mental training practice that ... brings you and your thoughts into the present, focusing on emotions, thoughts and sensations that you’re experiencing ‘in the now.’” It takes a lot of practice to learn to center and quiet your thoughts, and Boles warns that this can be tough in the beginning, especially for those who are grieving. “I was unable to sit without fidgeting, and focusing on my breath was a challenge,” she says. “These are both common for meditation novices. But for the grief stricken, in quiet times, our minds float to our deepest sorrows. I spent several evenings melting on the bathroom floor in a puddle of silent tears and tissues.” This doesn’t mean the benefits aren’t worth the effort. Heather Stang, who writes about mindfulness meditation, shares several benefits in Boles’s essay. She says mindfulness can “help give your mind a much-needed break from thinking” immediately after loss, “help you cultivate a calm and steady presence as you open to your experience of grief,” help you feel connected to those around you, and “help you acknowledge the ways that you have changed and rewrite your post-loss story” as you’re getting back to your life. (*Next Avenue*, 12/2) [Read more...](#)

*Hospice Analytics is the national sponsor of Hospice News Network for 2019. Hospice Analytics is an information-sharing research organization whose mission is to improve hospice utilization and access to quality end-of- life care. For additional information, please call Dr. Cordt Kassner, CEO, at 719-209- 1237 or see [www.HospiceAnalytics.com](http://www.HospiceAnalytics.com).*

Hospice News Network is published 45-46 times a year. Copyright, 2019. 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.