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Recent News On End-of-Life Care

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HOSPICE AND END-OF-LIFE CARE INCLUDED IN VISIONING OF THE FUTURE OF HEALTH CARE

What is the future of health care in the United States? Authors writing for the *Journal of the American Medical Association (JAMA)* are painting a picture that includes hospice and end-of-life care as central to the next generation of health care practice and patient well-being. In a series of papers recently published in JAMA, authors recommend that the US health care system be restructured to allow more efficient, targeted, and effective delivery of care. A linchpin of this restructuring is learning how to effectively care for individuals experiencing both chronic illness and the end of life.

One paper in particular stands out as a manifesto of sorts for what the US health care system might look like as it more fully integrates hospice and end-of-life care. “Workforce for 21st Century Health and Health Care” is authored by Steven H. Lipstein, MHA, president and chief executive officer of BJC HealthCare, and Arthur L. Kellermann, MD, MPH, dean of the F. Edward Hébert School of Medicine at the Uniformed Services University of the Health Sciences. The article summarizes the findings of the National Academy of Medicine’s writing team, who see a growing role for end-of-life care in the United States.

A large part of this shift in emphasis to providing quality care at the end of life comes as a result of a larger cultural shift in our health care system. Medical professionals, and the public as a whole, say the authors, are increasingly adopting a patient-centric focus in health care. Values, as discerned and expressed by patients and their families, are increasingly driving the development of the health care models that will be critical to health systems in the decades to come.

As part of living into this new cultural and clinical reality, Lipstein and Kellermann envision a new kind of health care workforce. **This workforce is interdisciplinary, and prepared to focus care on four distinct types of patients:**

1. People who are generally healthy. The generally healthy require health care services, of course, but their needs are generally of a routine nature – checkups, nutritional guidance, immunizations, and encouragement to exercise. Individuals in this category include women who are pregnant and giving birth. It includes young children who, whose health needs are significant, but predictable. “To promote health and prevent minor problems from developing into major ones, physicians, registered nurses, physician assistants, social workers, nutritionists, exercise physiologists, public health and other health professionals, will work together in multidisciplinary teams, and use telehealth and other technologies to extend their reach outside the walls of fixed healthcare facilities.”

2. People experiencing acute and major health episodes. Accidents happen. Auto accidents, falls, heart attacks – all manner of unpredicted, life-threatening events. For these patients, the authors recommend “high volume, high expertise centers” in order to “improve outcomes, reduce costs and improve education of future healthcare professionals.”

3. Individuals who experience ongoing, chronic medical issues. This is the next level of care – those who are neither routinely healthy, nor are experiencing an acute crisis, but who instead exhibit ongoing, chronic conditions that must be managed by health care professionals. The workforce that cares for these patients “should be interdisciplinary, and include paraprofessionals such as community health workers, primary care technicians, and others who can work with chronic diseases.” New technologies, such as home monitoring, will help to simultaneously improve care while reducing medical costs for chronically ill patients.

4. Those who are nearing the end of their natural lifespan. The authors identify the end of life as being a critical time, both for human beings in general, and for the health care system in particular. A different kind of care is needed here than in the other three groups. **The authors point to hospice and palliative care as key specialties that will become only more important as the US health care system evolves in the years and decades to come.** With nearly 3 million Americans reaching the end of life each year, this is a vital area for growth.

“To improve the care Americans receive in the 21st century, we need to recruit, educate, and sustain a diverse workforce of compassionate health professionals that are comfortable working in interdisciplinary teams, technically skilled, adept at using telehealth and health information technology, and consistently responsive to patients’ needs,” Kellermann said. (JAMA, 9/26, jamanetwork.com/journals/jama/fullarticle/2556009; Science Daily, 9/26, www.sciencedaily.com/releases/2016/09/160926105740.htm; Medical Xpress, 9/26, medicalxpress.com/news/2016-09-aging-experts-eldercare-workforce-priority.html)

ARTICLE SUGGESTS THAT “ENGAGED NEUTRALITY” ON PHYSICIAN-ASSISTED SUICIDE COULD BE BETTER FOR PATIENTS THAN ACTIVE RESISTANCE

As physician-assisted suicide (PAS) gains wider acceptance across the United States, more states are adopting legalization to allow it. With the recent adoption by California of an Oregon-style “Death with Dignity” law, the discussion around physicians’ role in providing lethal medication has become a live issue for more health care professionals than ever before. Traditionally, doctors have opposed PAS. **In the face of growing legalization of PAS, physicians are faced with difficult decisions. How do physicians uphold resistance to the practice of PAS, while still promoting the well-being of patients who legally choose it?**

Writing for the *Annals of Internal Medicine*, John Frye, MA, and Stuart J. Youngner, MD, argue that active resistance to PAS by health care professionals can actually be damaging to patients. By standing aside from the process, doctors may engage in what amounts to “patient abandonment,” - leaving patients to their own devices in the last moments of life – rather than giving them the care and accompaniment they deserve. As an alternative to this grim scenario, the authors suggest a policy of “engaged neutrality,” in which medical professionals actively provide care and assistance to patients choosing PAS, even if they disagree with their decision to choose life-ending drugs.

Ultimately, they argue, the role of the medical community is to provide care to patients, even if patient choices do not line up with their own. Their resistance to doing so may be causing unintended damage to patient well-being. “The refusal of professional organizations—including the American College of Physicians, American Medical Association, and American Osteopathic Association—to provide clinical guidance on the care of patients actively seeking assistance in dying does a disservice to the practicing physicians who are their members.” **Instead, physicians have an opportunity to minimize the potential harm of PAS by participating in its roll out, and watching carefully for problems that would affect patients.**

Many professional organizations for physicians oppose PAS based on patient welfare issues. For example, the authors say, There are “concerns [such] as decreased quality of end-of-life care, families and society coercing persons to seek death, vulnerable populations (such as the poor, uneducated, uninsured, and disabled) being encouraged to choose death over life, access to lethal medication by persons who have inadequate decision-making capacity, and creation of a slippery slope to (nonvoluntary) euthanasia.” **Yet the authors suggest that growing public acceptance and legalization of PAS is inevitable. In such a context, it is not a question of whether PAS will be allowed, but whether physicians will play a constructive and healing role in the midst of a health care system where PAS is a reality.**

Frye and Youngner envision a role for physicians as vigilant, helpful presences, who ensure that PAS is carried out in compassionate, patient-centric ways. **As PAS becomes normalized, they say, “Great care must be taken to ensure that helping patients die is never easier than providing them with the kind of care that would make them want to keep living. If these concerns are to be taken seriously, constructive engagement by organized medicine is essential.”**

The current tendency among physicians towards “studied neutrality” is insufficient for the demands of patient care. This is because taking a neutral position on whether PAS should be legal does little, if anything, to provide guidance for medical professionals who do, in fact, have to care for patients for whom PAS is a legal option. This puts individual physicians in the unenviable position of having to figure out how to effectively practice medicine in a post-PAS world, without any meaningful guidance from the wider world of practitioners.

Moreover, the authors argue, the “studied neutrality” of some organizations can directly harm patients. This includes hospices that forbid direct participation in PAS. In Oregon, for example, some hospices required staff to avoid being present when lethal medication was being ingested. Frye and Youngner suggest that in any other context this could be viewed as patient abandonment.

Both the avoidance currently being embraced by many physicians organizations, as well as the active engagement suggested by the authors, allow for diverse views. **One does not have to agree with PAS in order to actively engage in the health care of patients who choose it.** Yet engagement is key for providing patient care that is compassionate and responsible. Ultimately, an organization’s political position on PAS will be determined by the views of its physician members, but its engagement should be directed solely by the manifest needs of patients. **“When confronted with a patient’s request for assisted dying, physicians who consider moving forward should not feel unprepared or isolated. Their profession should support them in supporting their patients.”** (*Annals of Internal Medicine*, 9/27, annals.org/article.aspx?articleId=2556137&guestAccessKey=049beed1-a55e-4d8c-a840-847627690659; *NewsWise*, 10/3, www.newswise.com/articles/case-western-reserve-bioethicists-call-on-organized-medicine-to-support-patients-desiring-assisted-death-and-their-physicians)

HOSPICE AND END-OF-LIFE NOTES

*** CMS has released new data, explaining how it allocated the \$15 billion that was spent on hospice care in 2014.** “The Hospice Utilization and Payment Public Use File,” they say, “breaks down hospice costs and usage data by geographic location, beneficiary demographics, costs and individual provider characteristics. In 2014 alone, 1.3 million Medicare beneficiaries received a total of 92.3 million hospice care days, with each stay averaging about \$11,393 per beneficiary.” (*CMS*, 10/6, www.cms.gov/Newsroom/MediaReleaseDatabase/Press-releases/2016-Press-releases-items/2016-10-06.html; McKnight’s 10/10, www.mcknights.com/news/cms-releases-new-hospice-spending-utilization-data/article/546480/)

*** CMS recently posted hospice payment data. But how reliable is it?** “CMS has not provided the data in a readily accessible format and has not posted the data in a place that is easy to find on its website, according to public stakeholders and GAO’s observations,” GAO’s report said. “In addition, CMS does little to ensure the accuracy and completeness of the data.” (*Modern Healthcare*, 10/6, <http://www.modernhealthcare.com/article/20161006/NEWS/161009940>)

*** PBS features a video interview with Dr. BJ Miller of the Zen Hospice Project. “When people are dying, it changes how they live,” says Miller.** “The secret is that facing death has a

lot to do with living well.” (PBS, 10/6, www.pbs.org/newshour/bb/facing-death-doctor-sees-way-live-well/)

* ***Home Health Line (HHL)* reported on the release of the first year results of CAHPS survey data on hospices.** Survey results indicate that the lowest rated feedback was on whether hospices provide ample support to patients who are feeling anxiety and sadness. About 64.5% of responders say that the hospice team met patient and family need in this area. The highest rating reported by *HHL* was on keeping patients informed of their condition, with 78.2% satisfaction. Seventy-four thousand surveys were returned, representing about a 32% response rate. (*Home Health Line*, 10/10, <http://homehealthline.decisionhealth.com/Articles/Detail.aspx?id=523085>)

* **Two recent studies show that there are substantial disparities in outcomes between black and white patients at the end of life, in both hospitalizations and expenses.** “In unadjusted analyses, expenditures during the last 6 months of life were significantly higher for black and Hispanic patients than for white patients (about US\$52,000 and \$55,000 vs. \$39,000). In models adjusted for numerous clinical, demographic, socioeconomic, and geographic factors — and for existence of advance directives — differences in EOL expenditures across racial and ethnic groups were reduced by about half, but not abolished.” (*NEJM*, 10/3, www.jwatch.org/na42497/2016/10/06/racial-differences-end-life-care-hospitalization-and?query=etoc_jwgenmed&jwd=000020008345&jspc=US)

* **“Making end-of-life care decisions is about as real as it gets,” says Ann Brenoff in an article for The Huffington Post.** “We have seen friends reduced to human vegetables being carted off for more chemotherapy. Why?” (*Huffington Post*, 10/6, www.huffingtonpost.com/entry/making-end-of-life-care-decisions-is-about-as-real-as-it-gets_us_57ebeeae4b0c2407cdaf40b)

* **Is there a cap on human lifespan?** A study recently published in *Nature* suggests there is. “Despite increased life expectancy since the nineteenth century, progress appears to have stalled, suggesting humans’ maximum lifespan is ‘fixed and subject to natural constraints.’” (*HealthcareDIVE*, 10/6, www.healthcaredive.com/news/human-longevity-may-have-a-cap/427690/)

* **A *New York Times* article by Susan Gubar reflects on the different choices that people make in how they face the end of life.** Gubar shares about the experiences of two of her friends who approached the end of her differently. She realized that each one was “underscoring the importance of determining in one’s own way — according to one’s own values — the proper time to relinquish treatment. How difficult that decision must be: to figure out when interventions should be stopped, how active or passive a stance to take toward cancer, which physical deficits can be endured and which cannot.” (*New York Times*, 10/13, http://www.nytimes.com/2016/10/13/well/live/lessons-on-dying-from-david-bowie-and-my-friends.html?smid=tw-nytimeswell&smtyp=cur&r=1&utm_source=Member+Alert&utm_campaign=5c0d85a9ad-Member+Alert&utm_medium=email&utm_term=0_e1d9f6f769-5c0d85a9ad-150801781)

*** Peter DeMarco thanks the hospice caregivers who cared for him and his wife during her final days and hours alive.** “I will remember that last hour together for the rest of my life. It was a gift beyond gifts, and I have Donna and Jen to thank for it. Really, I have all of you to thank for it.” (*New York Times*, 10/6, www.nytimes.com/2016/10/06/well/live/a-letter-to-the-doctors-and-nurses-who-cared-for-my-wife.html?_r=0)

*** The American Cancer Society’s Cancer Action Network (ACS CAN) has issued grades to each US state for their treatment of pain management.** “Factors that the ACS CAN acknowledged as common to the states scoring high marks include recognizing pain as a driving force behind seeking medical treatment; awareness that opioids are a ‘legitimate treatment of pain’; and understanding the differences between addiction, dependence and pain medication tolerance.” (*Pain Medicine News*, 10/4, www.painmedicineneeds.com/Policy-Management/Article/10-16/Cancer-Society-Issues-Grades-for-Pain-Management-to-Each-State/38013/ses=ogst?enl=true)

*** The Drug Enforcement Administration has announced its plan to curtail the amount of prescription opioids being produced in the United States.** “Production of certain opioid medications, such as hydrocodone, will be reduced by 34 percent, the agency said in a news release. The DEA said it made the changes because legal prescriptions for these opioid medications have decreased, while illegal use of the drugs is on the rise.” (*HealthDay*, 10/5, consumer.healthday.com/bone-and-joint-information-4/opioids-990/dea-puts-quota-on-production-of-opioid-painkillers-715554.html)

PALLIATIVE CARE NOTES

*** Most hospital palliative care programs don’t have enough staff, according to a recent study published in *Health Affairs*.** “Most hospitals offer palliative-care services that help people with serious illnesses manage their pain and other symptoms and make decisions about their treatment while providing emotional support and assistance in navigating the health-care system. But the majority of these programs fail to meet national guidelines for staffing, a recent study found.” (*Washington Post*, 10/10, www.washingtonpost.com/national/health-science/most-hospital-palliative-care-programs-dont-have-enough-staff/2016/10/10/0102fbc0-8a46-11e6-875e-2c1bfe943b66_story.html; *Health Affairs*, 9/2016, content.healthaffairs.org/content/35/9/1690.abstract)

*** Does the Surprise Question actually work? The question - “Would you be surprised if this patient died in the next year?” - has emerged as a tool to encourage palliative care discussions, says Dr. Joshua Lakin.** Yet his team has found, “While [the Surprise Question] does help predict death, it missed a majority of patients who could have benefited from palliative care.” (*MedicalResearch.com*, 10/3, medicalresearch.com/author-interviews/the-surprise-question-may-help-stimulate-palliative-care-discussions/28515/)

*** The Journal of Palliative Medicine is offering free access to the following “High-Impact Articles” through Thursday, October 20th:**

- Factors Associated with Family Reports of Pain, Dyspnea, and Depression in the Last Year of Life (<http://online.liebertpub.com/doi/full/10.1089/jpm.2015.0391>)
- The Palliative Performance Scale Predicts Three- and Six-Month Survival in Older Adult Patients Admitted to the Hospital through the Emergency Department (<http://online.liebertpub.com/doi/full/10.1089/jpm.2016.0011>)
- Estimation of Risk in Cancer Patients Undergoing Palliative Procedures by the American College of Surgeons Risk Calculator (<http://online.liebertpub.com/doi/full/10.1089/jpm.2015.0482>)
- A Retrospective Study on the Effectiveness of Switching to Oral Methadone for Relieving Severe Cancer-Related Neuropathic Pain and Limiting Adjuvant Analgesic Use in Japan (<http://online.liebertpub.com/doi/full/10.1089/jpm.2015.0303>)
- A Patient-Reported Outcome Instrument to Facilitate Timing of End-of-Life Discussions among Patients with Advanced Cancers (<http://online.liebertpub.com/doi/full/10.1089/jpm.2015.0459>)

* **The Global Palliative Care Quality Alliance (GPCQA) is hosting the 2nd Annual Quality Matters Conference on Thursday, October 20th.** The national conference will be held virtually, online, and there is no cost to attend. Participants register online. (GPCQA, <http://www.gpcqa.org/qmc>)

OTHER NOTES

* **Reuters reports that the price of drugs used for physician-assisted suicide have spiked in recent years.** “The average cost of secobarbital increased from \$388 in 2010 to \$2,878 in 2016, according to the researchers.” (*Reuters*, 10/10, www.reuters.com/article/us-health-death-drug-costs-idUSKCN12A2HJ)

* **Could New Jersey become the sixth state to legalize physician-assisted suicide?** An “Aid in Dying” bill has passed committee and is heading to the state House of Representatives for a vote. (*NJTV New*, 10/10, www.njtvonline.org/news/video/aid-dying-bill-passes-committee-heads-house-vote/)

* **The New York Times editorial board spoke out in favor of physician-assisted suicide.** “There is no compelling reason to deprive them [patients] of physician-assisted dying as one option alongside high-quality, innovative palliative care.” (*New York Times*, 10/10, www.nytimes.com/2016/10/10/opinion/aid-in-dying-movement-advances.html?ref=todayspaper&r=0)

* **The editorial board of *The Denver Post*, “after a lot of soul-searching,” encourages voters to reject Proposition 106, the current proposed legislation on physician-assisted suicide.** Though they supported an earlier bill, the board worries, they say, about the reporting requirements in the current measure. The fear the measure “would entice insurers to drop expensive treatments for terminal patients even when medical advances might add months or years more to a life that a patient may wish to take. (*The Denver Post*, 10/11,

<http://www.denverpost.com/2016/10/11/no-on-proposition-106-aid-in-dying-measure-lacks-proper-safeguards/>)

* **Archbishop Desmond Tutu says that, when the time comes, he wants the option of physician-assisted suicide.** “In refusing dying people the right to die with dignity, we fail to demonstrate the compassion that lies at the heart of Christian values. I pray that politicians, lawmakers and religious leaders have the courage to support the choices terminally ill citizens make in departing Mother Earth. The time to act is now.” (*Washington Post*, 10/6, www.washingtonpost.com/opinions/global-opinions/archbishop-desmond-tutu-when-my-time-comes-i-want-the-option-of-an-assisted-death/2016/10/06/97c804f2-8a81-11e6-b24f-a7f89eb68887_story.html?utm_term=.658fb679e5fa)

* **Washington, DC, is voting on physician-assisted suicide. Could this be a dangerous move?** “Given that options and choices already exist in end-of-life care that are highly regulated by a larger professional and ethical community, the legislation is simply not necessary,” argue two DC-area professors. (*Washington Post*, 10/4, www.washingtonpost.com/news/acts-of-faith/wp/2016/10/04/d-c-is-about-to-vote-on-physician-assisted-death-heres-why-its-dangerous/)

* **As Colorado prepares for a vote on PAS law, residents are wrestling with the ethical implications.** “When is it going to be a duty to die?” asks one resident, who opposes Proposition 106. “That’s what euthanasia is, and when is it going to stop being a choice?” (*NPR*, 10/11, www.npr.org/sections/health-shots/2016/10/11/497540453/colorado-wrestles-with-ethics-of-aid-in-dying-as-vote-looms)

* **Google is investing in Aspire Health.** “Aspire Health, the palliative care company co-founded by former Senate Majority Leader Bill Frist, has closed a \$32 million funding round that was led by another big name: GV (formerly Google Ventures), the venture capital arm of tech giant Alphabet Inc. (Google’s parent company).” (*Nashville Business Journal*, 10/3, www.bizjournals.com/nashville/news/2016/10/03/googleinvests-in-frist-founded-aspire-health.html)

* **Can training in empathy and the humanities help reduce physician burnout?** Two articles published in *KevinMD* explore the possibilities. (*KevinMD*, 10/9, www.kevinmd.com/blog/2016/10/empathy-can-help-physician-burnout.html; 10/10, www.kevinmd.com/blog/2016/10/medical-humanities-can-help-physician-burnout.html)

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