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Update

States across the country continue to reject doctor-prescribed suicide bills

After California legalized doctor-prescribed suicide last year, activists campaigning for the law's passage expressed sentiments akin to "nothing can stop us now in other states." But, during the first four months of 2016, lawmakers in 10 states did just that—they stopped them.

Assisted-suicide bills were voted down in committees, removed for further study, or pulled by sponsors due to a lack of support in Alaska, Arizona, Colorado, Hawaii, Iowa, Maryland, Minnesota, Nebraska, Utah, and Wisconsin. In addition, Alabama lawmakers are currently considering a bill (HB 157) that would explicitly prohibit doctor-assisted suicide. If passed, the bill would make "aid-in-dying" a felony and participating health care providers would have their licenses suspended

or revoked by the appropriate state licensing board.

Many states have defeated prescribed-suicide bills multiple times. Legislators in Hawaii, for example, have rejected more than 25 such bills since 1998. The latest 2016 bill (SB 2373) died after the Consumer Protection & Health Committee chose not to even hear it. [*Civic Beat*, 2/22/16]

But assisted-suicide supporters are, if anything, very persistent. Several sponsors of the bills defeated in 2016 have vowed to reintroduce their measures next year or during the next legislative session.

What happened in New Jersey earlier this year is a good example. On January 12, 2016, the last day that the 2014-2015 prescribed-suicide bill (S

382) could be voted on in the Senate, the bill's sponsors decided they didn't have enough votes to pass the measure, so it officially died. A few weeks later, on February 4, the same bill was reintroduced in the newly commenced 2016-2017 legislative session under a new number, A 2451.

Supporters of the failed Colorado bill (HB 16-1054) are attempting to take their advocacy efforts directly to voters. The Colorado Secretary of State has approved two separate assisted-suicide initiatives for signature gathering. Supporters will have to get over 98,000 valid voter signatures to qualify each measure for the November 2016 ballot. Initiative 100—referred to as "Liberty at Life's End"—is a proposed constitutional amendment that would

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Canadian government introduces controversial death bill

Last year, when the Canadian Supreme Court struck down long-standing laws banning euthanasia and assisted suicide as being unconstitutional, the justices stayed their ruling until June 6, 2016, to allow the federal government time to come up with legislation that would set protocols and requirements to regulate the death-inducing practices. On April 14, the recently installed Liberal government complied and introduced Bill C-14, a bill to amend the country's criminal code to allow for "medical assistance in dying" (MAID).

As defined in the bill, MAID includes both euthanasia (the act of a "doctor or nurse practitioner" administering a lethal substance to a person who requests it) and assisted suicide (the prescribing or "providing" of that substance so that the person can self-administer it to cause death).

The bill stipulates that, in order to qualify for MAID, a person must:

- be at least 18 years-old, a Canadian resident, and capable of making health care decisions,
- have a "serious and incurable illness, disease, or disability" that is in an "advanced state of irreversible decline in capability" and causing intolerable "physical or psychological suffering," and
- have made a voluntary request and given "informed consent" for death assistance.

There is no requirement for a time-left-to-live prognosis—like six months or less. The person's "natural death" must simply be "reasonably foreseeable... without a prognosis

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Questions arise as California prepares to enact prescribed-suicide law on June 9

While California legislators passed the End of Life Option Act on September 11, 2015, and Gov. Jerry Brown signed it into law three weeks later, the assisted-suicide law won't go into effect until June 9, 2016. That's because the Act, which failed to pass during the regular 2015 legislative session, was cleverly resurrected and passed during a special session called by Gov. Brown expressly to find ways to save the state's Medicaid program, called Medi-Cal, from a pending \$1.1 billion shortfall. Any bill passed during that special session could not be enacted until 90 days after the session officially ended, which occurred this year on March 10.

When the prescribed-suicide bill was being debated last year, some people questioned whether it was actually a cost-cutting measure since it was taken up during the Medi-Cal special session, but the bill's sponsors assured everyone it was not, saying it was simply a compassionate response to the suffering of the terminally ill.

But people are beginning to ask the cost-cutting question again after Gov. Brown's proposed 2016 Budget contains the addition of \$2.3 million dollars to cover the assisted-suicide costs for Medi-Cal patients. Those costs would likely include the price the state would pay for a lethal dose of the drug-of-choice, Seconal—\$5,400 per dose, after recent price hikes by the pharmaceutical company that makes it—or about \$500 for a new lethal mix of drugs recently concocted by Washington State assisted-suicide advocates. Reportedly, California officials are considering using the

cheaper drug mix, which, according to its creator, tastes worse, takes longer to end life, burns the mouth, but works as well as Seconal. [ABC News, 4/3/16]

California would face additional costs if Medi-Cal covered prescribed-suicides. According to the special session's Assembly Finance Committee analysis of the new law, first-year costs (setting up a state medical "aid-in-dying" database, hiring new people to collect data, etc.) could add up to \$323,000, with costs for subsequent years running about \$245,000. But, even with these expenses, the Finance Committee analysis concluded that there will be a potential "savings in Medi-Cal based on the Medi-Cal program choosing to cover this end-of-life option." [Assembly Committee on Finance, Analysis of ABX2-15, 9/4/15]

There's little question that paying \$500 to \$5,400 for a one-time lethal drug dose instead of many thousands of dollars each month for ongoing treatments would save Medi-Cal money. But a disturbing picture develops when one considers the findings of a 2015 University of California–Davis study. The study, which looked at disparities in cancer care among different health insurance programs, found that Medi-Cal patients with breast, colon, prostate, lung, and rectal cancers were diagnosed at more advanced stages, received lower quality care, and had less favorable survival rates than patients covered by other insurers. [Parikh-Patel et al., "Disparities in Stage at Diagnosis, Survival & Quality of Cancer Care in CA by Source of Health Insurance," UC-Davis, Oct. 2015]

Add to that the fact that 22 counties in California lack access to community-based palliative care and 19 lack in-patient palliative care programs [California Healthline, 12/1/15] and the question becomes: How many Medi-Cal patients will needlessly opt for assisted suicide rather than endure lower quality care with little or no access to pain and symptom relief? ■

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necessarily having been made as to the specific length of time that they have remaining."

The death-requesting patient must sign a written MAID request. If the patient is not able to do so, then "another person" can sign and date it on the patient's behalf. The request must also be signed by two "independent" witnesses. After the request is signed, there is a required 15-day waiting period before the patient can receive MAID, but that does not apply if the medical team feels that the patient's death is imminent or the patient could lose the ability to give informed consent before the 15-day period expires.

In addition to doctors and nurse practitioners being given immunity from "culpable homicide" for ending patients' lives, the bill would extend that immunity to other people who "do anything for the purpose of aiding a medical practitioner or nurse practitioner to provide a person with medical assistance in dying"—even if the doctor, nurse practitioner, or other person "has a reasonable but mistaken belief about any fact that is an element of the [criminal] exception." [Bill C-14, 4/14/16; available at www.patientsrightscouncil.org]

PRC legal consultant Wesley J. Smith called the Canadian bill "a prescription for getting away with murder." "Since the death doctor need not be present at the demise," he wrote, "the bill creates an unprecedented license for family members, friends—heck, a guy down the street—to make people dead." "Canada has just paved the way for a person, hungry for an inheritance or ideologically predisposed, to get away with the perfect murder," he explained. [Blog, *National Review*, 4/14/16]

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allow euthanasia—deadly drugs administered by another person—for a patient with an "incurable, life-limiting medical condition," which could include conditions that are not considered terminal. It would also allow the induced death of incompetent patients, such as dementia patients, if they have a previously signed advance directive requesting death. Reportedly, this initiative is opposed by Compassion & Choices (C&C), the former Hemlock Society and current activist group pushing state assisted-suicide measures.

The second ballot initiative, Initiative 124 (the "Colorado End-of-Life Options Act"), uses the language that C&C has developed over the years for assisted-suicide bills in targeted states. While it is most likely that C&C is the force behind the measure, there is no mention of the organization in the official documents submitted to the state.

Note: *The Patients Rights Council (PRC) recommends that readers stay up-to-date on the status of any assisted-suicide measure in their respective states.* ■

“Unknowns” point to big credibility problems with OR assisted-suicide reports

On February 4, 2016, the Oregon Public Health Division (OPHD) issued its latest report on known doctor-prescribed suicide deaths in 2015. It is the 18th annual report that the OPHD has issued since the Oregon Death with Dignity Act was enacted in 1997.

In 2015, the number of lethal drug prescriptions (written by a record-high 106 doctors) increased 41%, from 155 in 2014 to 218 in 2015. Also, a record 132 patients reportedly died from prescribed lethal drugs in 2015. That’s a 26% jump over the reported assisted-suicide deaths in 2014. Only five patients—2% of the 218 patients who received lethal drug prescriptions and 4% of the 132 who took the drugs and died—were referred for a psychiatric evaluation.

According to the OPHD, of the 218 patients who received lethal drug prescriptions in 2015, 125 took the drugs and died, 50 did not ingest the drugs but died naturally, and seven people died in 2015 after taking lethal drugs that were prescribed in “previous years.” The OPHD lists the “ingestion status” of the remaining 43 patients as “unknown.”

As in previous years, prescribed-suicide advocates have been using the Oregon reports in legislatures across the country in an attempt to convince lawmakers that Oregon-style assisted-suicide laws are safe, problem-free, and without any abuses. But the sheer amount of unknown data in the reports render such claims implausible.

For example, the 2015 report shows that, when the patient ingested the lethal drugs, a doctor was present in 15 cases, another “care provider” was present in 13 cases, and “no provider” was present in 6 cases. (See table on the right.) But it’s the “unknown” statistic that is most significant. In 98 cases—that’s 74% of all the reported 2015 prescribed-suicide deaths—the OPHD doesn’t know if anyone was present at the most critical time in the whole assisted-suicide process, when the patient takes the lethal drugs. That means that the OPHD has no clue if the patient took the deadly dose voluntarily (as required by the assisted-suicide law), or if it was disguised in food and

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Reported Assisted-Suicide Deaths in Oregon 1998-2015

Report data supplied by lethally prescribing doctors, pharmacist reports, and death certificates.¹

Figures are those reported by the state in the 2015 report.

Categories	1998 - 2012	2013	2014	2015	TOTAL
No. of reported assisted-suicide deaths	681 ²	73	105	132	991 ²
No. of unreported assisted-suicide deaths	Unknown ¹	Unknown ¹	Unknown ¹	Unknown ¹	Unknown ¹
No. of reported lethal prescriptions written	1051	121	155	218	1545
No. of doctors who wrote lethal prescriptions in a given year	? ³	62	83	106	? ³
No. of cases where prescribing doctor was present when lethal drugs were ingested:					
Other care provider present:	→	→	133 ⁴	15	148
No provider present:	→	→	243 ⁴	13	256
Unknown:	→	→	81 ⁴	6	87
			332 ⁴	98	430
No. of cases where prescribing doctor was present at the time of death:					
Other care provider present:	→	→	121 ⁴	14	135
No provider present:	→	→	268 ⁴	13	281
Unknown:	→	→	383 ⁴	103	486
			17 ⁴	2	19
No. of patients referred for psychiatric evaluation	→	→	47 [5.5%]	5 [3.8%]	52 [5.3%]
Patients’ reasons for requesting assisted suicide:					
Inability to do enjoyable activities	→	→	758 [89%] ⁴	127 [96%]	885 [90%]
Loss of autonomy	→	→	782 [92%] ⁴	121 [92%]	903 [92%]
Loss of dignity	→	→	579 [79%] ⁴	98 [75%]	677 [79%]
Lost control of bodily functions	→	→	428 [50%] ⁴	46 [36%]	474 [48%]
Being a burden	→	→	342 [40%] ⁴	63 [48%]	405 [41%]
Inadequate pain control or concern about it	→	→	211 [25%] ⁴	37 [29%]	248 [25%]
Financial implications of treatment	→	→	27 [3%] ⁴	3 [2%]	30 [3%]
Complications after lethal drugs were ingested:					
Regurgitation	→	→	22 ⁴	2	24
Patient regained consciousness	→	→	6 ⁴	0	6
Other	→	→	1	2	3
Unknown	→	→	330 ⁴	105	435
Reported incidents of physician non-compliance with the assisted-suicide law ⁵	22	0	0	0	22
Penalties imposed for non-compliance with the assisted-suicide law ⁵	0	0	0	0	0

Notes:

1. The Oregon Public Health Division (OPHD), the agency responsible for overseeing the practice of doctor-prescribed suicide, has acknowledged that it has no way of knowing if deaths went unreported or if the information provided by prescribing doctors are accurate or complete. The Pharmacy Dispensing Report simply asks for general information (i.e., patient & physician names and drugs prescribed) but has no data on patient cases. Death certificates, by law, do not even indicate drug overdose as the true cause of death. Also, the total number of deaths reported for specific years since 1998 are increased retrospectively when OPHD receives data on an assisted-suicide death that was not previously included in that year’s annual report.
2. The 2015 Report reflects the official totals from 1998 to 2015. However, some of the previous totals for recent years, as listed in each year’s individual report when issued, were changed in the 2015 Report with no explanation given.
3. Since the OPHD reports do not identify the individual, lethally-prescribing doctors, there is no way to determine the total number of doctors who wrote prescriptions beyond a year at a time.
4. In the 2015 Report, this is the combined total for 1998 through 2014. In some categories, the totals may differ from figures reported in previous years. No explanation for the change was given.
5. This category is not included in the 2015 Report’s statistical table. Regarding doctor compliance, the text states, “no referrals were made to the Oregon Medical Board for failure to comply with DWDA requirements.” The 22 cases of non-compliance listed above were cited in previous annual reports. No doctor has been penalized for non-compliance.

Source:

Oregon Public Health Division, “Oregon’s Death with Dignity Act - 2015 Data Summary,” released 2/4/16.

All 18 annual reports are available online at: <http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/ar-index.aspx>

Study finds most euthanized Dutch psychiatric patients were isolated & lonely

A troubling study on the increasing practice of psychiatric patient euthanasia in the Netherlands was recently published in the American Medical Association's journal *JAMA Psychiatry*. The study focused on the characteristics of the patients euthanized for psychiatric reasons and how the practice is regulated.

Researchers, headed by Dr. Scott Y. H. Kim, a psychiatrist and bioethicist at the US National Institutes of Health (NIH), studied 66 euthanasia and assisted-suicide (EAS) cases involving patients with psychiatric disorders. Most (70%) were women and most had chronic, often severe, conditions, with previous psychiatric hospitalizations and suicide attempts. Depressive disorders were diagnosed in 55% of the cases, while 26% had some form of psychosis and 42% had various anxiety disorders.

One of the most revealing findings is that 56% of the patients were socially isolated and lonely. Researchers cited doctor's comments on a woman's and a man's euthanasia report as descriptive of how

loneliness had affected the patients' sense of self-worth. Woman: "The patient indicated that she had had a life without love and therefore had no right to exist." Man: "The patient was an utterly lonely man whose life had been a failure."

In 18 cases (27%), patients requested euthanasia from a doctor who was not involved in their prior care. Fifteen of those patients were euthanized by doctors at the End-of-Life Clinic, a mobile euthanasia service created especially for patients whose own doctors had refused their euthanasia requests. For 27 patients (41%), the doctor who terminated their lives was a psychiatrist. But for 39 patients (59%), the euthanizing doctor was usually a general practitioner.

Researchers also reported that there were a total of 110 psychiatric euthanasia cases reviewed post-mortem by the regional Dutch Euthanasia Review Committees between 2011 and 2014, but the committees only found one case where the doctor failed to meet the established eu-

thanasia "due care criteria." The case involved a chronically depressed woman in her 80s who had asked the End-of-Life Clinic to help her die. "The physician was not a psychiatrist, did not consult psychiatrists, was unaware of the Dutch Psychiatric Association Guidelines," researchers wrote, "and yet 'had not a single doubt' about the patient's prognosis."

But, even if general practitioners did confer with psychiatrists and there was a disagreement regarding the patient's prognosis, the researchers found that the Euthanasia Review Committee generally deferred to the judgement of the euthanizing doctor. [*JAMA Psychiatry*, 2/10/16]

In an editorial on the study's findings, Dr. Paul S. Applebaum, a psychiatrist from Columbia University, wrote this about the fact that most of the euthanized psychiatric patients were socially isolated and lonely: "[This] evokes the concern that physician-assisted death served as a substitute for effective psychosocial intervention and support." [*JAMA Psychiatry*, 2/10/16] ■

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Dr. Catherine Ferrier, a geriatric specialist at Canada's McGill University Health Center, agrees. "An heir to your will can sign you up on your behalf," she wrote. "There is a sense that the lawmakers believe everyone who considers killing a sick person has the best of intentions and no ulterior motive. Have they never heard of elder abuse?" [*Ottawa Citizen*, 4/14/16]

Even euthanasia and assisted suicide advocates have voiced strong objections to the bill, calling it too restrictive. They had expected that the legislation put forth by the Liberal government would contain most of the 21 extremely broad recommendations issued last February by Parliament's Special Joint Committee on Physician-Assisted Dying. Those recommendations included:

- MAID be available to terminally ill and non-terminally ill patients, people with psychiatric conditions, and, after a specified study period, "mature minors" as well.
- Advance directives requesting MAID be allowed for those diagnosed with a condition that will likely result in loss of competency (Alzheimer's disease and other forms of dementia).
- Doctors who conscientiously object to ending a patient's life must provide the patient with an "effective referral" to a doctor or nurse practitioner who will comply. [Special Joint Committee on Physician-Assisted Dying Report, "Medical Assistance in Dying: A Patient-Centered Approach," 2/16]

Shanaaz Gokool, head of Canada's euthanasia activist group Dying with Dignity (DWD), said she is "deeply disappointed" in the bill and called it a "flagrant misinterpretation" of the Supreme Court's ruling because it doesn't go far enough. [*The Economist*, 4/19/16]

Josh Patterson, executive director of the British Columbia Civil Liberties Association, the group that challenged the constitutionality of the euthanasia and assisted suicide laws all the way to the Supreme Court, warned that the proposed bill, as written, could be challenged in court. "By excluding people who are suffering intolerably on account of a mental illness, by excluding mature minors, and by refusing to respect advance requests, this legislation plainly violates the Charter rights of suffering Canadians," he said. [ipolitics.ca.com, 4/14/16]

Regarding doctors who want to opt out of the MAID practice, the bill does not specifically address that issue, leaving it up to the local provinces to determine whether practitioners will be forced to refer patients to those willing to terminate their lives.

One thing is for certain, the bill will be hotly debated as Parliament prepares to vote on the measure before June 6. Some Senators are contemplating amending it to be less restrictive or voting it down to let the Supreme Court ruling govern the practice. However, the bill is expected to pass, since the Liberal Party has a strong majority in the House of Commons. [CP, 4/16/16] ■

Advance Care Planning – sounds good, but...

Jason Negri

“Advance Care Planning” has been getting more attention over the past years. From the federal Patient Self Determination Act of 1990, to the rise in state advance directive legislation, to the institution of National Healthcare Decisions Day (every April 16), it seems that more people are giving some thought to the health care issues they may face in the future and what they can do to insure that their wishes are honored if they are unable to make medical decisions for themselves. Our society’s increased attention to this issue and the conversations we’re having are good things. Raising awareness is important, as is planning for the future.

With this in mind, it would seem beneficial that the U.S. Department of Health & Human Services (HHS) has instituted new regulations to promote advance care planning (ACP). These regulations lay out how doctors are to be paid through the Medicare program for holding counseling sessions with their patients to discuss their health care wishes. The idea is that doctors will now be able to submit a bill to Medicare and get paid for talking with their Medicare patients about ACP. This gives doctors an incentive to have these very important conversations—talks that most people recognize are needed.

As of the last intensive study on this issue (in 2003),¹ it was discovered that:

- Fewer than 50% of the severely or terminally ill patients studied had an advance directive in their medical record;
- Only 12% of patients with an advance directive had received input from their physician in its development; and
- Between 65% and 76% of physicians whose patients had an advance directive were not aware that it existed.

While there is a need for ACP discussions, and even though these conversations are voluntary for the patient, there are also some real concerns regarding the new HHS regulations.

Will all advance directives meet with government approval?

Some health care advance directives identify a surrogate decision maker—someone authorized by patients to make medical decisions for them if patients are unable to communicate or make their own decisions. This type of advance directive is prudent to have in place for every adult, regardless of their age, marital status, health, etc.

However, there is another kind of advance directive called a “living will,” which, rather than identifying a surrogate decision-maker, gives all decision-making authority to an attending physician and sets down, in advance, the medical care that a person does (or more often, does *not*) want if they become incapacitated. These documents can be particularly dangerous:

- During the advance care planning discussion, notes taken by the doctor regarding a patient’s wishes will very likely be put in electronic form and made part of the patient’s permanent medical record. But it’s highly unlikely that, when the time comes, the doctor reading and acting upon the patient’s recorded wishes will be the same doctor who originally made the notes. Will the new attending physician accurately interpret the patient’s wishes? The patient’s trusted doctor of 20 years may know that the patient’s statement, “I don’t want medical interventions,” meant only CPR and being put on a ventilator, but a future attending physician in an unknown setting might interpret it to mean *all* medical interventions, including, for example, the provision of food and fluids or antibiotics—without which the patient would die.
- It is practically impossible for anyone to predict in advance what sort of care they would or would not want in the future when they face a currently unknown condition. And if the doctor’s notes from the original ACP conversation are part of the patient’s permanent medical record—likely in a POLST-type form—they could be interpreted as a standing doctor’s order, which can be acted upon by any medical provider any time in the future without further input from the patient or anyone else.

With these dangers in mind, the problem with the HHS regulation is that its wording makes a distinction between an Advance Care Plan and the designation of a health care decision maker:

The measure would calculate the percentage of patients age 18 years and older... *that have an advance care plan or surrogate decision maker* documented in the clinical record.² (Emphasis added.)

This distinction suggests that, to the HHS, having an identified surrogate decision maker is not an advance care plan.

The new regulation doesn’t just *include* the “living will” model in its understanding of an ACP, it seems to portray living wills as *the only acceptable ACPs there are*, as distinguished from a document that identifies a surrogate decision maker. If this and future regulations tie incentives and reimbursements to the creation of an ACP, the “living will” model (with all its risks) will likely be preferred over advance directives that allow the patient to name a trusted decision maker.

What’s the government’s motivation?

The government’s stated hope is that encouraging doctors to have these conversations with their patients will result in “enhanced patient autonomy and reduced hospitalizations and in-hospital deaths.”³ But what else is at play? A few years ago

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unwittingly consumed by the patient, or if the patient was forced to take the drugs (the last two actions being clearly illegal).

Since 2001—the first year that OPHD began keeping track of the care providers' presence at the time of ingestion—there have been a total of 430 cases (47%) marked “unknown” out of the total 921 reported assisted-suicide cases.

In the 2015 statistics for lethal drug complications after ingestion, the OPHD reported that, for 105 cases (80%), it is unknown whether complications occurred or not. Since the first annual report was issued in 1998, possible complications were listed as “unknown” for 435 patients (44%) out of the total 991 patients who died using Oregon's doctor-prescribed suicide law. [OPHD, “Oregon Death with Dignity Act–2015 Data Summary,” 2/4/16]

It should be of great concern that 40% to 80% of the data is missing from report categories that are directly related to patient safety and abuse. It begs the question: How can the claim that Oregon's assisted-suicide experience is problem- and abuse-free be credible when so much of what is actually occurring is officially “unknown”? ■

Survey finds many doctors uncomfortable with patient end-of-life talks

A national poll of 736 primary care physicians and specialists in 50 states found that virtually all the doctors surveyed consider end-of-life and advance care planning discussions with their Medicare patients important, but only 29% have had any formal training on how to go about having that conversation.

The poll, “Conversation Stopper: What's Preventing Physicians from Talking with Patients about End-of-Life and Advance Care Planning,” was commissioned by The John A. Hartford Foundation, the California Health Care Foundation, and the Cambia Health Foundation. Now that Medicare pays doctors \$86 when they have end-of-life care discussions with their patients, the survey's goal was to identify the barriers that have been preventing or inhibiting doctors from having these conversations.

Almost half of the doctors (46%) said that they often feel unsure about what

to say to patients, and 60% said that they frequently don't initiate the discussion because they aren't sure if it's the right time to do so. One physician explained, “If you have [the talk] too early, it may not be meaningful or clear enough. If you have it too late, they're struggling with their illness and may feel... that you're giving up on them.”

Only 29% of the doctors worked in a practice or health care system that had a system for assessing patients' wishes and goals. Another 24% said there was no place in their electronic health records to indicate an advance care plan and, for those who could, only 54% were able to electronically access the patient's actual wishes.

Interestingly, over half of the doctors said they had not discussed their own end-of-life treatment wishes with their personal physicians. [John A. Hartford, Cambia Health, & CA Health Care Foundations, Press Release, 4/14/16; NPR, 4/15/16; *Boston Globe*, 4/15/16] ■

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when the Affordable Care Act (Obamacare) was first proposed, it contained a similar reimbursement provision that was quickly dropped amid concerns that it would pressure people to refuse treatment and might ration care based upon the government's assessment of the patient's quality of life (the so-called “death panels”). Are we seeing a rehashing of this controversial idea, quietly implemented via a federal regulation?

Some say this current proposal is simply cost-cutting couched as good patient decision-making. The Association of American Physicians and Surgeons says that the ACP payments will “create financial incentives to persuade patients to consent to the denial of care.”⁴ And an article in the *New York Post* claims that “seniors are nudged to forego life-sustaining procedures and hospital care to go into hospice.”⁵ There is the strong likelihood of a conflict of interest when the person/entity driving the conversation stands to save a lot of money by not having to provide treatment.

The context in which these conversations take place matters a great deal. It's one thing to discuss Advance Care Planning with your loved ones or in an attorney's office. But having it take place in a doctor's office—where the patient is already in a vulnerable position, where patients could be nudged into signing a living will instead of designating a surrogate decision maker, where the bias could be towards withholding treatment—ought to raise serious red flags that cause us to proceed with caution. ■

¹ HHS, “Advance Care Planning, Preferences for Care at the End of Life” (2003). Available at <http://archive.ahrq.gov/research/findings/factsheets/aging/endliferia/endria.html> (last accessed March 10, 2016).

² 80 Fed. Reg. 39840, at 39883 (2015). Available at www.federalregister.gov (last accessed March 10, 2016).

³ *Ibid*, at 39883 (2015). Available at www.federalregister.gov (last accessed March 10, 2016).

⁴ Association of American Physicians & Surgeons, “Call them Death Incentives, Suggests AAPS” (July 20, 2015). Available at http://www.aapsonline.org/index.php/article/call_them_death_incentives_suggests_aaps/ (last accessed March 10, 2016).

⁵ *New York Post*, “‘End of Life Counseling’: Death Panels Are Back.” (July 12, 2015). Available at <http://nypost.com/2015/07/12/end-of-life-counseling-death-panels-are-back/> (last accessed March 10, 2016).

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News briefs from home & abroad . . .

● **Missouri & Kansas:** Simon Crosier (in Missouri) and Megan Barnes (in Kansas) were both born with the chromosomal birth defect Trisomy 18. Hospital staff told their parents that babies with this condition fail to thrive and have a short life expectancy of no more than a year. Simon died on December 3, 2010, after living only 88 days. Megan died on December 29, 2004, at the age of 19. Both died after their doctors placed a do-not-resuscitate order (DNR) on their hospital charts without their parents' knowledge or consent. According to Sheryl Crosier, Simon's mother, Simon's doctor not only issued the DNR, but also administered drugs that made breathing difficult, ordered only enough tube feeding to keep Simon comfortable but not nourished, and turned off the monitor tracking Simon's vital signs and life support without parental approval. Likewise, Megan's parents said that all their requests for full life support interventions, after their daughter had been hospitalized for virus-caused dehydration, were overruled by Megan's attending physician without their knowledge. Both sets of parents contend that, if the DNR had not been placed without their consent, if the hospital's futile care policy had been disclosed, and if the doctors had not made value judgments that Simon and Megan were not worthy of life-sustaining treatment because of their birth defects and resulting disabilities, their children would have survived their hospitalizations. [*Medical Futility Blog*, 2/15/16; *Lake Expo News*, 3/2/16; *Topeka Capital-Journal*, 3/29/16, 4/9/16]

As a result of these cases, bills have been introduced in both Missouri and Kansas that would require the written permission of at least one parent or legal guardian before doctors can issue a DNR for or withhold life-sustaining treatment from patients under 18 years of age. The bills, called Simon's Law, also require that hospitals and medical facilities disclose any futile care policies currently in place. Missouri's HB 1915 had a public hearing on February 16, and Kansas' SB 437 was passed in the Senate on March 22 by a

vote of 37 to 3 and was subsequently sent to the House for consideration.

● **Wisconsin:** A resolution to change the official assisted-suicide position of the Wisconsin Medical Society from longstanding opposition to neutrality failed to be adopted during the Society's annual meeting. The resolution would have also required medical professionals to refer death-requesting patients to physicians willing to prescribe lethal drugs if the practice were legal in the state. A coalition of organizations against legalizing prescribed suicide submitted opposition statements to the Society on behalf of the elderly and people with disabilities. They also cited the impact the resolution would have on Wisconsin doctors.

● **New York:** End of Life Choice New York (formerly named Compassion & Choices of New York) along with three patients and five doctors have appealed the October 16, 2015, ruling by Manhattan Supreme Court Justice Joan Kenney that dismissed their case challenging New York's statutes prohibiting doctor-assisted suicide. In their appeal request, the plaintiffs argued that Justice Kenney's ruling failed to address their claim that "aid-in-dying" is not assisted suicide and that the death practice is comparable to other legal medical practices such as terminal sedation, a practice in which a patient is rendered unconscious by sedation and all food and fluids are withheld until the patient dies from dehydration. Eleven national disability rights groups, including Not Dead Yet, filed amicus briefs in support of Justice Kenney's dismissal ruling. [*New York Law Journal*, 12/16/15; Not Dead Yet blog, 1/6/16]

After an appellate court hearing last February, Kathryn Tucker, Compassion & Choices' former legal director and veteran litigator who is representing the patient plaintiffs, said, "I think we got the sense today that this court feels

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the plaintiff's should have their day." The ruling in the case, *Myers v. Schneiderman*, is pending. [*Capital New York*, 2/4/16]

- **USA:** Drug shortages are becoming a real problem for American patients, resulting in treatment rationing and triage protocols in many cases. The worst part, according to a *New York Times* article, is that patients rarely know when their treatment is being altered, diluted, or substituted because of shortages. One example is the use of a now scarce, decades-old drug used to prevent the patient from hemorrhaging during and after open-heart surgery. Dr. Brian Fitzsimons, an anesthesiologist at the Cleveland Clinic, the country's largest cardiac center, explained that the clinic did "military-style triage," allowing only patients with the highest risk of bleeding to have the drug. The other patients never knew that they didn't get this previously standard treatment. "The patient is asleep," he said. "The family never knows about it." A survey of oncologists found that 83% said they weren't able to prescribe the preferred chemotherapy drug for a patient at least one time in the previous six months.

The American Society of Health-System Pharmacists has listed more than 150 drugs and therapeutics as having "inadequate supplies." The reasons for the shortages include manufacturing problems, federal safety crackdowns, and drugmakers stopping production of less profitable drugs. How the drug rationing is handled by health facilities and doctors across the country varies widely. [*New York Times*, 1/29/16]

- **United Kingdom:** In response to numerous British cases where do-not-resuscitate orders (DNRs) have been placed in patients' medical records without their knowledge and consent or the consent of their families, a new form has been drawn up to replace DNR forms and encourage better communication among medical providers, patients, and patients' families. The new 2-page form, called Emergency Care and Treatment Plan, is expected to be introduced into the National Health System (NHS) later this year. But the form, which will not be a mandatory replacement for DNRs, is already receiving criticism from experts in the field who say it is so complicated and confusing that doctors won't fill them out correctly or engage in the needed discussions with patients and their relatives. Lawyer Merry Varney—attorney for the family of Janet Tracey, who died after a DNR was placed on her hospital chart against her will and without her family's knowledge—said the new form does not remedy the problem of paternalistic doctors who think they should be the ones to decide if a patient needs a DNR or whether to initiate communication with the patient or loved ones. [*Daily Mail* (UK), 2/17/16]

- **New Zealand:** The New Zealand Medical Association (NZMA) has strongly affirmed its position that euthanasia and doctor-assisted suicide are unethical practices. In its submission to Parliament's Health Select Committee, which is studying the social, medical, cultural, financial, ethical, and philosophical implications of legalizing the death-inducing practices, the NZMA wrote:

- The NZMA is opposed to both the concept and practices of euthanasia and doctor-assisted suicide.
- This NZMA position is not dependent on euthanasia and doctor-assisted suicide remaining unlawful. Even if they were to become legal, or decriminalized, the NZMA would continue to regard them as unethical.

[NZMA, "Submission to the Health Select Committee," 2/16]

- **Australia:** In May 1995, the Northern Territory (NT) Parliament passed the world's first euthanasia law, the "Rights of the Terminally Ill Act." After the law took effect on July 1, 1996, four people died with the help of Dr. Philip Nitschke, earning him the nickname "Dr. Death." That law, however, was overturned by the Australian (federal) Parliament on March 24, 1997, effectively banning the NT (and other territories) from legalizing euthanasia and assisted suicide.

But last December, Sen. David Leyonhjelm introduced a bill (No. 44) in the federal parliament to reinstate NT's original euthanasia law and permit the practice's legalization in the other territories as well. Leyonhjelm said there was overwhelming support for his bill. But that apparently was not the case. While the bill was debated in March, it failed to pass the Senate before the session ended on April 17. [Parliament Update, 4/17/16; AAP, 12/1/15; *Sky News*, 10/14, 15] ■

The Patients Rights Council is a human rights group formed to promote and defend the right of all patients to be treated with respect, dignity and compassion and to work with individuals and organizations to resist attitudes, programs and policies which threaten the lives of those who are medically vulnerable. To those ends, the PRC compiles well-documented and up-to-date information on a whole range of end-of-life issues, including health care advance directives, POLST forms, futile care policies, health care reform, and doctor-prescribed death.

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