YEAR-END REPORT - 2020

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Long-Term Care
End-of-Life Issues

This Issue Brief was written by Louise W. Seiler, B.A., a contributing writer.

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I. BACKGROUND AND INTRODUCTION

The U.S. has seen an “increased demand by individuals and families for active participation in medical decision-making” that has likely produced corresponding changes in expectations about end-of-life care, says the APA. This has been caused in part, by “the fact that the baby boom generation is increasingly dealing with end-of-life care for their parents and the prospect of their own mortality.” Other factors, including increased longevity and the fact that “the dying process and death have moved from taking place at home to medical settings” have impacted how end-of-life issues are presently addressed and handled by those confronting or experiencing a terminal illness. [FN2]

As might be expected, these issues continue to top the list of ethical dilemmas faced by hospitals. [FN3] Moreover, a *Dartmouth Atlas of Health Care* study pointed out tendencies toward overtreatment (based on assumptions that “more” care equals “better” care) and variations in treatment as well as a frequent disregard for patient wishes. The study suggested that hospital systems could impact ways in which treatment methods at the end of life are approached by “moving the nation toward more organized, integrated care.” [FN4] In addition, many hospice care providers are confronting the moral pressures of serving patients who are outliving standard actuarial schedules: for example, *The New York Times* reported that those afflicted with either dementia or Alzheimer's disease “now form a majority of hospice consumers, and their average stays are far longer.” Because these longer stays often exceed Medicare reimbursement limits, hospice providers can potentially be hit with federally imposed assessments as a result of being unable, ethically, to discontinue care to those having “outlived their profit potential.” [FN5] On the other hand, a *New England Journal of Medicine* study concluded that a large number of Americans who could have been receiving hospice care were not, due mainly to the fact that “many aspects of hospice care are misunderstood by both physicians and patients” [FN6] often resulting in delayed referrals and underutilization of services.

A study [FN7] conducted by the Harvard Medical School and funded by the National Cancer Institute found that hospice and end-of life issues are not discussed by physicians or other health care providers with approximately 50 percent of patients deemed terminally ill. [FN8] Haiden Huskamp, lead study author and a Harvard Medical School associate professor, cited several possible reasons for the delay, including patients' unrealistic expectations about life expectancy, the choice to believe in a better outcome, and lack of physician training in handling “some delicate conversations.” A study conducted by the *Archives of Internal Medicine* showed that doctors often choose to stop all further contact with patients once end-of-life care has begun. [FN9] The year-long study, led by a University of Washington researcher and focusing on 31 physicians, 55 of their chronically ill patients, 36 family caregivers and 25 nurses, found that feelings of abandonment existed among caretakers and patients alike once hospice programs were initiated and doctor contact had ended. Another study carried out by the Dana-Farber Cancer Institute in Boston showed that advanced-cancer patients who did not talk with their doctors about end-of-life care had health care expenses in the last week of life that were 36 percent higher than those of patients who did have discussions concerning such care. [FN10] The study pointed out that “higher costs were typically the result of more intensive, life-prolonging care, yet patients who received such intensive care usually didn't live longer.”

Only about 35 percent of people have actually had discussions with their loved ones about end-of-life care, according to a report coauthored by a University of Massachusetts Medical School professor. A survey found that a majority of those contacted?62 percent? hadn't spoken about their end-of-life care plans with either their healthcare agent or proxy, or their medical provider and just 10 percent

had spoken to both, the report stated. Also, 71 percent of respondents said that it was harder to plan for end-of-life care than to distribute their assets after death. However, once end-of-life conversations happened with doctors, 78 percent of respondents said they were “not at all” difficult; two thirds of respondents said having the same conversation with someone other than a healthcare provider wasn't difficult. [FN11]

In a recent study, researchers have found that making sure residents' care preferences are consistently recorded and updated in medical records is crucial to providing quality end-of-life care, in a recent study. The report states that advanced care planning is an important step for patients and families to take, especially at a time when nearly a quarter of hospitalized older adults are not able to make their own end-of-life decisions. The study was conducted by a team of researchers at the Indiana University Center for Aging Research and the Indiana University School of Nursing, and published online in the Journal of Pain and Symptom Management.

Inconsistencies in the way care preferences are documented and carried out by nursing homes and hospitals may mean a patient's' preferences are not honored. The team's report, set out to measure care consistency with documented care practices, and how healthcare providers can improve that consistency. The researchers recommend five best practices for providers to ensure consistency with their residents care preferences: 1) documenting each resident's specific treatment preferences, such as “do not place feeding tube” instead of “comfort care,” in the medical record; 2) making sure treatment preferences are recorded in a consistent format and location in each medical record; 3) reviewing and updating preferences regularly as residents' clinical conditions change; 4) creating data collection strategies to document decisions to withhold medical interventions; and 5) implementing a consistent measurement approach, such as a required percentage for agreement with care preferences, that can be used to compare with other providers. [FN12]

Because end-of-life issues, including those pertaining to hospice care and advanced care directives, are intrinsically related to the issues surrounding long-term care?especially as they apply to the elderly as well as maturing baby boomers?developing trends and pending legislation will continue to be monitored by HPTS. For additional information on long-term, see Health Policy Tracking Service, Long-Term Care, a service of Thomson Reuters.

According to the report, the medical advances of the past century have shifted the leading cause of death from infectious disease to chronic disease, resulting in longer life spans. Accordingly, it is expected that most people today will die at an advanced age following a period of chronic illness. Furthermore, the nation's oldest baby boomers turned 65 during 2001, causing the elderly to make up an even larger portion of the U.S. population. Thus, quality of life and quality of dying are increasingly important societal concerns.

Lonely older adults are burdened by more health symptoms and receive more intensive end-of-life care than their peers who don't suffer from loneliness, researchers at the University of Michigan have found. [FN13] The investigators studied records of 2,896 decedents older than 50 years who died between 2004 and 2014, after excluding those who were ineligible for surveys assessing loneliness or had missing or incomplete loneliness or symptom data. They found that one third of the decedents were lonely. Compared with nonlonely individuals, lonely decedents were more likely to use life support in the last two years of life and to die in a nursing home. No significant differences in other measures of intense care (late hospice enrollment, number of hospitalizations, or dialysis use) or likelihood of advance care planning were observed, the study noted. The researchers determined that lonely older people may be burdened by more symptoms and exposed to more intense end-of-life care compared with nonlonely people. Clinicians must do more to screen for and intervene in cases of loneliness among older adults at the end of life, not only during the dying period, they concluded.

II. IMPACT OF COVID-19

Coronavirus cases are surging within nursing facilities in states hard hit by the latest onslaught of COVID-19. An analysis of federal data from 20 states for *The Associated Press* finds that resident deaths more than doubled, from 318 a week to 699, according to the study by University of Chicago health researchers Rebecca Gorges and Tamara Konetzka. ***[FN14]*** Equally concerning, weekly infection cases among nursing home staff in surge states more than quadrupled, from 855 the week ending May 31, to 4,050 the week ending October 25. Infected staffers not yet showing symptoms are seen as the most likely way the virus gets into facilities. Then, when those unwitting staffers test positive, they are sidelined from caring for residents, raising pressures on remaining staff.

Although the Trump administration has allocated $5 billion to nursing homes, shipped nearly 14,000 fast-test machines with a goal of supplying every facility, and tried to boost stocks of protective equipment, the data calls into question broader White House policy, that pushes states to reopen, as the virus rebounds in communities surrounding the vulnerable nursing home populations.

“Trying to protect nursing home residents without controlling community spread is a losing battle,” said Konetzka, co-researcher of the study, and nationally recognized expert on long-term care. “Someone has to care for vulnerable nursing home residents, and those caregivers move in and out of the nursing home daily, providing an easy pathway for the virus to enter.”

Nursing homes and other long-term care facilities account for about 1% of the U.S. population, but represent 40% of COVID-19 deaths, according to the COVID Tracking Project. CMS noted different ways the administration has worked to help nursing homes, saying now that its focus is on ensuring that residents and staff would “immediately” have access to a vaccine once approved.

But Konetzka said her research has shown that nursing home quality has no significant effect on cases and deaths once community spread is factored in. “It's not like the high-quality facilities have figured out how to do things better,” she said. Other academic experts have reached similar conclusions.

The 20 states analyzed in the study were Alaska, Arkansas, Iowa, Idaho, Indiana, Kansas, Kentucky, Minnesota, Missouri, Montana, Nebraska, New Mexico, North Dakota, Ohio, Oklahoma, South Dakota, Utah, Wisconsin, West Virginia, and Wyoming. They were selected because they're now seeing their highest hospitalization rates for COVID-19.

CMS Waives Some Medicare, Medicaid, CHIP Requirements to Help Hospices

Under ? 1135 of the Social Security Act, the HHS Secretary is authorized to waive certain Medicare, Medicaid, and Children's Health Insurance Program program requirements once the President has declared an emergency through the Stafford Act, [FN15] and the Secretary has declared a Public Health Emergency. President Trump issued such an emergency declaration on March 13, 2020, and the HHS Secretary issued a PHE on January 31, 2020 in response to the spread of COVID-19. As a result of this authority, CMS can grant waivers to ease certain requirements for affected providers.

CMS approved hundreds of waiver requests from healthcare providers, state governments, and state hospital associations in 15 states in the early stages of the pandemic. On March 30, 2020, CMS announced an array of blanket waivers and new rules designed to help healthcare providers respond to the COVID-19 outbreak. [FN16] With the announcement of blanket waivers, other states and providers do not need to apply for these waivers and can begin using the flexibilities immediately.

For hospice services in particular, CMS has provided the following waivers: [FN17]

• *Use of Volunteers*. CMS is waiving the requirement that use volunteers (including at least 5% of patient care hours).

• *Comprehensive Assessments*. CMS is waiving certain requirements related to updating comprehensive assessments of patients. This waiver applies the timeframes for updates to the comprehensive assessment found at 42 CFR 418.54(d). Hospices must continue to complete the required assessments and updates, however, the timeframes for updating the assessment may be extended from 15 to 21 days.

• *Non-Core Services*. CMS is waiving the requirement for hospices to provide certain non-core hospice services during the national emergency, including the requirements for physical therapy, occupational therapy, and speech-language pathology.

• *Onsite Visits for Hospice Aide Supervision*. CMS is waiving the requirement that a nurse conduct an onsite supervisory visit every two weeks. This would include waiving the requirements for a nurse or other professional to conduct an onsite visit every two weeks to evaluate if aides are providing care consistent with the care plan, as this may not be physically possible for a period of time.

Audits and Medical Reviews to Resume

CMS will resume enforcement activities, including targeted probe and education audits, on August 3, regardless of the status of the federally declared COVID-19 national emergency, *Hospice News* reports. [FN18] The agency had suspended audits and medical reviews by Medicare Administrative Contractors (MACs) as of March 30. Hospice utilization among Medicare decedents rose to exceed 50% for the first time during 2018, according to CMS. As utilization climbs, so does the amount of dollars CMS spends on hospice care, spurring the agency to step up enforcement in an effort to control costs. Medicare hospice expenditures rise by about $1 billion annually.

CMS indicated that hospices that are selected for review should discuss any hardships stemming from the outbreak with their contractor if their ability to respond to the audit in a timely fashion is uncertain. Nevertheless, hospice providers are uncertain about the prospect of facing an audit during a pandemic. This includes concerns about staff safety as they return to the office to pull documents. Audits can be triggered by issues such as longer lengths of stay, live discharges, and recertification of a patient for hospice. Documentation is a key component of each of these processes.

Many hospice providers express uncertainty about their ability to weather an audit. Even prior to the pandemic, fewer than 50% of hospices indicated that they were ready for a federal audit or additional document request, according to a 2019 survey of 170 organizations by Optima Health. As MACs review hospices' compliance with CMS rules, some providers have also expressed concern that the contractors may not be up to speed regarding the evolving regulatory landscape brought on by the pandemic. CMS issued a number of 1135 waivers to relax regulations to allow hospices to focus on patient care rather than administrative compliance activities.

Over One-third of COVID-19 Deaths Tied to Long-Term Care Facilities

Fatalities from COVID-19 in long-term care facilities account for at least a third of the deaths in 26 states; and more than half the deaths in 14 of those states. [FN19] The data is based on reported tallies from a variety of care facilities, including nursing homes, adult care residences, and other skilled nursing care settings, as published by the Kaiser Family Foundation. [FN20] The report comes as states prepare to meet a federal reporting deadline.

As of May 6, the foundation reported 5,215 people died from the virus in long-term care facilities in New York ? 20% of the state's total number of dead. New Jersey had the second-highest rate with 4,556 reported cases in their facilities, 53% of the state's total death toll. According to the report, New Hampshire and Pennsylvania reported the highest share of coronavirus deaths ? 72% and 70% respectively. However, the total deaths behind those ratios vary widely from state to state. In the case of New Hampshire, 66 of 114 total deaths occurred in long-term care facilities. Whereas, in Pennsylvania the slightly lower percentage represents a much greater death toll ? 2,355 of 3,364 deaths, according to the *NPR* article.

According to a *New York Times* database, at least 54,000 residents and employees of nursing homes and long-term care facilities have died from the coronavirus, accounting for 43 percent of virus-related deaths in the United States. [FN21] The database relies on reports from states, counties, and individual facilities, as well as some data from the federal government, tracking 282,000 known coronavirus cases at some 12,000 facilities.

Most of the country's largest clusters have emerged in nursing homes, prisons, and food processing facilities?where social distancing is difficult or impossible, and in some cases shutting down was not an option. In nursing homes with large outbreaks, The *Times* found that a higher proportion (17 percent) of people with the virus died, compared to about 5 percent of all known coronavirus patients. The *Times* provides a searchable list of all nursing homes known to have had at least 50 coronavirus cases. [FN22]

Under an interim final rule released by CMS on May 8, 2020, [FN23] states must report coronavirus-related information to the CDC on a weekly basis. The CDC expects to make the information available sometime before the end of the month.

Nursing Home Restrictions

On March 13, 2020, the Centers for Medicare & Medicaid Services (CMS) issued revised guidance for infection and control and prevention of coronavirus disease (COVID-19) for nursing homes, including specific guidance for visitation for certain compassionate care situations, such as end-of-life. Hospice guidance from CMS has not changed. The updated visitation guidance for nursing facilities, with the exception for end-of-life situations, is as follows:

For all facilities nationwide: Facilities should restrict visitation of all visitors and non-essential health care personnel, except for certain compassionate care situations, such as an end-of-life situation. In those cases, visitors will be limited to a specific room only. Facilities are expected to notify potential visitors to defer visitation until further notice (through signage, calls, letters, etc.). Note: If a state implements actions that exceed CMS requirements, such as a ban on all visitation through a governor's executive order, a facility would not be out of compliance with CMS' requirements. In this case, surveyors would still enter the facility, but not cite for noncompliance with visitation requirements.

Additional detail for compassionate situation entry:

For individuals that enter in compassionate situations (e.g., end-of-life care), facilities should require visitors to perform hand hygiene and use Personal Protective Equipment (PPE), such as facemasks. Decisions about visitation during an end of life situation should be made on a case by case basis, which should include careful screening of the visitor (including clergy, bereavement counselors, etc.) for fever or respiratory symptoms. Those with symptoms of a respiratory infection (fever, cough, shortness of breath, or sore throat) should not be permitted to enter the facility at any time (even in end-of-life situations). Those visitors that are permitted, must wear a facemask while in the building and restrict their visit to the resident's room or other location designated by the facility. They should also be reminded to frequently perform hand hygiene.

Hospice workers are considered health care workers and should be permitted to enter the facility. Additional guidance on exceptions for health care workers: Facilities should follow CDC guidelines for restricting access to health care workers. [FN24] This also applies to other health care workers, such as hospice workers, EMS personnel, or dialysis technicians, that provide care to residents. They should be permitted to come into the facility as long as they meet the CDC guidelines for health care workers. Facilities should contact their local health department for questions, and frequently review the CDC website dedicated to COVID-19 for health care professionals. [FN25]

'Compassionate Care' Visits

While the federal government has largely left the decision to reopen nursing facilities up to the states, the Centers for Medicare & Medicaid (CMS) released guidelines on June 23 designed to encourage safe visitation of residents in nursing homes. [FN26] CMS notes that the “compassionate care” exemption to the ban on non-essential visitors does not apply only to end-of-life situations. It cites a few examples of compassionate care situations: a resident who was living with their family before recently being admitted to a nursing home, to lessen the trauma of a change in their environment and sudden lack of family; or allowing someone to visit a resident whose friend or family member recently passed away. CMS suggests that nursing homes may decide to create safe spaces within the facility, such as see-through separation walls or other such areas so that residents may physically see their family members, or outside visitation. CMS also recommends setting up appointment times to ensure control of the number of visitors at any given time. Also, CMS warns that such visits should not be conducted on a routine basis, and left the final decision up to local officials.

Use of Telehealth During Pandemic and Beyond

During the COVID-19 outbreak, one of the first steps CMS took in response to the COVID-19 public health emergency was to temporarily expand the scope of Medicare telehealth to allow beneficiaries across the country?not just in rural areas?to receive telehealth services from any location, including their homes. CMS also added 135 allowable services, more than doubling the number of services that beneficiaries could receive via telehealth. Additionally, CMS allowed telehealth technology to fulfill many requirements for clinicians to see their patients face-to-face in different health care settings, including hospice.

A number of the telehealth flexibilities implemented by CMS impact hospice providers. During the pandemic, hospices may provide interdisciplinary services via telemedicine or audio as long as the patient is receiving routine home care level of care and those

telemedicine services which are audio-only services are capable of meeting the patient and caregiver needs. The CARES Act, designed to help the economy and essential industries survive the impact of the COVID-19, also contained provisions related to hospice telehealth, including permitting practitioners to recertify patients via telemedicine appointments rather than face-to-face encounters. A number of stakeholders, as well as members of Congress, have called on CMS to make the actions permanent.

CMS itself has indicated that it is reviewing the waivers to see which can be implemented on a long-term basis. “With these transformative changes unleashed over the last several months, it's hard to imagine merely reverting to the way things were before. As the country re-opens, CMS is reviewing the flexibilities the administration has introduced and their early impact on Medicare beneficiaries to inform whether these changes should be made a permanent part of the Medicare program,” CMS Administrator Seema Verma wrote in the journal Health Affairs. [FN27]

On the legislative front, a bipartisan group of representatives introduced the Protecting Access to Post-COVID-19 Telehealth Act on July 16, 2020, to help protect providers and patients who have benefited from telehealth services during the pandemic. The act expands the use of telehealth after the end of the crisis by eliminating most geographic and originating site restrictions in Medicare and establishing the patient's home as an eligible distant site so patients can receive telehealth care at home and doctors can still be reimbursed; authorizes CMS to continue Medicare reimbursement for telehealth for 90 days beyond the end of the public health emergency; makes the disaster waiver authority permanent, enabling HHS to expand telehealth in Medicare during all future emergencies and disasters; and requires a study on the use of telehealth during COVID-19, including its costs, uptake rates, measurable health outcomes and racial and geographic disparities. [FN28]

Other legislation addressing the expansion and extension of telehealth includes:

• 2019 CONG US HR 7338, introduced January 25, 2020, the Advancing Telehealth Beyond COVID-19 Act of 2020, to continue telehealth policies implemented in the CARES Act and expand access for seniors

• 2019 CONG US S 4216, the KEEP Telehealth Options Act of 2020, introduced July 20, 2020, calling for HHS to conduct a detailed study of telehealth use during COVID-19

• 2019 CONG US HR 7078, introduced June 1, 2020, the Evaluating Disparities and Outcomes of Telehealth During the COVID-19 Emergency Act, would call for HHS to conduct a detailed study of telehealth use during COVID-19, and

• 2019 CONG US S 3993, introduced June 17, 2020, the Equal Access to Care Act, would allow care providers to use telehealth in any state to treat patients anywhere for up to six months after the pandemic.

Pandemic Hits Hospice Revenues

A majority of hospice providers (60%) anticipate a decrease in annual revenues in 2020, according to recent research conducted by the National Association for Home Care & Hospice (NAHC). [FN29] The survey, which was conducted over the first three weeks of May 2020, sought information on a broad range of issues, including the extent to which hospices have employed telecommunications technology to help meet patient care needs.

Among the contributing factors to revenue drops is a decline in hospice patient admissions and referrals amid the public health emergency. While nearly two-thirds (61 percent) of hospices that responded to the NAHC survey have admitted confirmed COVID-19-positive patients on to service, more than half of respondents saw a decrease in admissions during March 2020 as compared with March 2019. More than a quarter saw a 15% drop or more. Nearly 71% of the hospices reported declining referrals and admissions from nursing facilities, along with 63% experiencing declines in hospital referrals and roughly half seeing a decrease from community referral partners.

A majority of the providers also cited increased costs of supplying staff with personal protective equipment (PPE), with hospices calling for more federal funding of PPE supplies among increased costs and high demand.

Not surprisingly, according to the report, more than 95% of hospices have had existing patients refuse visits due to fears associated with risk of exposure to COVID-19. And while hospices have been able to provide technology-based visits to continue patient care in some cases, nearly 24 percent of the hospices in the survey were able to substitute virtual visits in only limited or no cases. A large proportion?more than 84 percent?of hospices participating in the survey are using telecommunications technology to provide services to Medicare hospice patients and a similar proportion (approximately 82 percent) use two-way audio-visual communications (among other technologies) for patient care.

Deciding Who Gets Ventilators and Critical Care Resources

As the COVID-19 pandemic intensifies, providers are encountering shortages of critical care resources, such as ventilators and ICU beds, and the real possibility that they may have to decide which patients receive the life-saving care, and which do not. In *JAMA* Viewpoint, Douglas B. White, MD, MAS, and Bernard Lo, MD, consider the critical question: When demand for ventilators and other intensive treatments far outstrips the supply, what criteria should guide these rationing decisions? [FN30]

Categorically Excluding Large Groups of Patients From Receiving Mechanical Ventilation: Although certain professional society guidelines and some state recommendations exclude from access to ICUs large groups of patients with certain comorbid conditions

(such as heart failure, severe chronic lung disease, end-stage renal disease, and severe cognitive impairment), the authors find such exclusions not explicitly justified, and ethically flawed. The criteria for exclusion (long-term prognosis and functional status) are selectively applied to only some types of patients, rather than to all patients being considered for critical care. Moreover, categorical exclusions are too rigid to be used in a dynamic crisis, when ventilator shortages will likely surge and decline episodically during the pandemic, and such exclusions violate a fundamental ethical principle: use the means that are least restrictive to individual liberty to accomplish the public health goal.

Focus on Survival to Hospital Discharge: The commonly recommended approach to allocate ventilators to those patients most likely to survive to hospital discharge with treatment is inadequate because it ignores other relevant considerations, such as the number of years of life saved, or giving individuals equal opportunity to pass through the stages of life?childhood, young adulthood, middle age, and old age. Persons who have essential responsibilities in saving lives during the pandemic, such as health care workers and first responders, also deserve heightened priority. Also, it should be made explicit that ventilators will not be allocated on the basis of morally irrelevant considerations, such as sex, race, religion, intellectual disability, insurance status, wealth, citizenship, social status, or social connections.

Recommendations for a Multiprinciple Allocation Framework: All patients who meet usual medical indications for ICU beds and ventilators are eligible and are assigned a priority score using a 1 to 8 scale based on (1) patients' likelihood of surviving to hospital discharge, assessed with an objective measure of acute illness severity; and (2) patients' likelihood of achieving longer-term survival based on the presence or absence of comorbid conditions. Also, individuals who perform tasks vital to the public health response are given heightened priority. In the event that there are ties in priority scores, life-cycle considerations are used as a tiebreaker, with priority going to younger patients, who have had less opportunity to live through life's stages.

Withdrawing Life Support from One Patient to Provide It to Another: While the need to “reallocate” ventilators when capacity is overwhelmed is acknowledged, it will be distressing to health care workers, patients, and families, because in ordinary clinical care ventilators are withdrawn only if the family agrees. The following steps could improve such agonizing decisions:

• ventilator use should be presented to patients and families as a time-limited therapeutic trial, not an unlimited promise.

• the duration of the trial of ventilation must not be too brief, to avoid a “rapid cycling” of withdrawing ventilators from patients who, if treated for several more days, would have survived.

• a triage officer or team, not the treating physician, should make decisions about allocating and discontinuing ventilators.

• when mechanical ventilation is discontinued, comprehensive palliative care is imperative. Family members of patients near death should be granted compassionate use of personal protective equipment if possible so that they can be with the dying patient. Health care workers will also need emotional support.

In conclusion, the authors urge hospitals and states to establish and implement policies that more fairly allocate scarce critical care resources and that better support dying patients and their families.

CMS Waives Nurse Training Tasks During COVID-19 Pandemic

Hospice nurses will be relieved of hospice aide in-service training tasks so they can spend more time with patients under a new policy announced on April 9 by the Centers for Medicare & Medicaid Services (CMS). “It's all hands on deck during this crisis. All frontline medical professionals need to be able to work at the highest level they were trained for,” CMS Administrator Seema Verma said. [FN31] CMS's workforce changes apply immediately and address supervision, licensure and certification, and other limitations in various healthcare settings. They are part of an array of temporary regulatory waivers and new rules issued recently by CMS and intended to help the American healthcare system respond to COVID-19.

On-site Testing Could Reduce Isolation Facing Residents

American Health Care Association (AHCA) President and CEO Mark Parkinson says there are two keys to safely reuniting eldercare facility residents and their families after COVID-19 lockdowns: bringing infection numbers down in adjacent communities, and universal testing that includes on-site visitor tests, *McKnight's* reports. [FN32] In a Sunday Fox News interview, Parkinson was asked what scenario would allow residents and families to reconnect. He acknowledged the devastating consequences of facility lockdowns on residents' quality of life. Despite staff attempts to connect families virtually through apps like Facetime, “there's just no alternative to being together, and then the tragic scenes of people dying without their loved ones — it's horrible,” he said. [FN33]

When determining whether to open facilities, the leading consideration must be infection levels in surrounding communities, as this will determine the risk level inside an eldercare facility, he said. Adequate testing of all staff and residents will offer further protection, he added. And the “ideal” situation would be the addition of “on-site testing throughout the summer,” he concluded. “[W]e do recognize it's extremely important to get these folks back with their families.”

Dementia Mortality Increases with Lockdowns

Beyond the staggering U.S. deaths caused directly by COVID-19, the *Washington Post* reports that more than 134,200 people have died from Alzheimer's and other forms of dementia since March. [FN34] That is 13,200 more U.S. deaths caused by dementia than expected, compared with previous years, according to an analysis of federal data by the *Post*.

Legislation

Federal

2019 CONG US HR 8156, introduced September 1, 2020, would extend use of telehealth to conduct a face-to-face encounter prior to recertification of eligibility for hospice care, for a limited period, during the COVID emergency.

Colorado

• 2020 CO H.B. 1425 (NS), adopted June 29, 2020, concerning hospital patient visitation rights during the COVID-19 pandemic, to balance the need to reduce virus transmission with the benefits of having family members present during illness, especially at the end of life, hospitals are encouraged to follow infection prevention protocols and identify ways to improve visitation policies while still following best practices.

• 2020 CO S.B. 212 (NS), engrossed June 12, 2020, concerning reimbursement for health care services (including hospice) provided through telehealth.

Louisiana

• 2020 LA H.B. 98 (NS), engrossed on October 14, 2020, would require inpatient healthcare facilities to adopt policies to allow for members of the clergy to visit patients or residents, including, but not limited to, those patients receiving end-of-life care, during a state of public health emergency; would provide that such policies may allow for visitation by clergy of a patient or resident who is incapacitated upon request of a family member or legal representative of the patient or resident.

• 2020 LA S.B. 12 (NS), adopted October 28, 2020, providing access for patients of hospitals and residents of nursing homes, assisted living facilities, and other adult residential care homes to members of the clergy who volunteer to minister and provide religious sacraments and services, counseling, and mental health support during COVID-19 and other public health emergencies. Special consideration given to patients or residents receiving end-of-life care.

Minnesota

2019 MN H.F. 23 (NS) and 2019 MN S.F. 18 (NS), introduced October 12, 2020, relating to the COVID-19 pandemic, would modify hospice bill of rights.

Massachusetts

2019 MA H.B. 4667 (NS), introduced April 21, 2020, would require long-term care facilities, assisted living residences, and elderly housing facilities shall report daily, to municipal health departments and to each resident's health care proxy, emergency contact legal guardian, or other legally authorized representative the number of known COVID-19 positive cases and mortalities by residents and staff, each in its own category. The department shall make this information available on its website.

Minnesota

• 2019 MN H.F. 13 (NS), introduced November 12, 2020, would modify long-term care infection control requirements, modify hospice and assisted living bill of rights, and prohibit termination of assisted living services during a peacetime emergency.

• 2019 MN H.F. 18 (NS) and 2019 MN S.F. 14 (NS), introduced September 11, 2020, relating to the COVID-19 pandemic, would modify hospice bill of rights.

• 2019 MN H.F. 84 (NS), introduced July 14, 2020, regarding COVID-19, modifying electronic monitoring requirements; modifying Board of Executives for Long-Term Service and Supports fees; establishing private enforcement of certain rights; establishing a private cause of action for retaliation in certain long-term care settings; modifying infection control requirements in certain long-term care settings; modifying hospice and assisted living bills of rights; establishing consumer protections for clients receiving assisted living services; prohibiting termination of assisted living services during a peacetime emergency; establishing procedures for transfer of clients receiving certain long-term care services during a peacetime emergency; requiring the commissioner of health to establish a state plan to control SARS-CoV-2 infections in certain long-term care settings; establishing the Long-Term Care COVID-19 Task Force; changing provisions for nursing homes, home care, and assisted living; requiring a report; and appropriating money.

• 2019 MN S.F. 23 (NS) and 2019 MN H.F. 20 (NS), introduced December 14, 2020, would modify long-term care and assisted living provisions regarding health-related electric monitoring requirements, create a SARS-CoV-2 infections state plan; and create a long-term care COVID-19 task force.

• 2019 MN S.F. 4606 (NS), introduced on May 12, 2020, and 2019 MN H.F. 4664 (NS), introduced on May 11, 2020, would limit liability for products and supplies made, sold, and donated in response to COVID-19 to governmental and health care entities, including hospices; addressing premises liability related to COVID-19; and precluding liability when conduct complies with government-issued guidance related to COVID-19, to take effect retroactively from March 13, 2020.

Mississippi

2020 MS S.B. 3049 (NS), engrossed June 24, 2020, would create the Mississippi Back-to-Business Liability Assurance Act; define the duty of care for premises owners; provide liability protection for individuals, state and local government, associations, for-profit and nonprofit entities, religious and charitable organizations; provide safe harbor for compliance with public health guidance; provide liability protection for products made, sold, or donated in response to COVID-19 and related circumstances.

New Hampshire

2020 NH Legis. Serv. Exec. Ord. 2020-42?Emerg., approved May 11, 2020, authorizing temporary health partners to assist in responding to COVID-19 in long-term care facilities, by assisting with comfort and end-of-life care, among other activities.

New Jersey

• 2020 NJ A.B. 2370 (NS), adopted October 19, 2020, establishes compassionate release program for inmates that are suffering from a terminal condition, disease, or syndrome, or a permanent physical incapacity; repeals law that establishes medical parole.

• 2020 NJ A.B. 3999 (NS) and 2020 NJ S.B. 2380 (NS), amended/substituted on July 27, 2020, concerning employment benefits and coronavirus disease 2019 infections contracted by essential employees, including hospice employees.

• 2020 NJ A.B. 4485 (NS) and 2020 NJ S.B. 2784 (NS), amended/substituted September 24, 2020, would dedicate personal protective equipment to long-term care facilities, home health agencies, hospice care providers, and certain community-based providers during a public health emergency.

• 2020 NJ A.B. 4767 (NS) and 2020 NJ S.B. 3006 (NS), introduced October 8, 2020, would restore civil liability of nursing homes and related facilities, including hospice, during public health emergency.

• 2020 NJ S.B. 2380 (NS), adopted September 14, 2020, concerning employment benefits and coronavirus disease 2019 infections contracted by essential employees, including hospice facility employees.

• 2020 NJ S.B. 3041 (NS), amended/substituted December 7, 2020, would require the department of health to publish the total number of COVID-19 deaths in long-term care facilities.

• 2020 NJ A.B. 5129 (NS), introduced December 10, 2020, and 2020 NJ S.B. 3269 (NS), introduced December 14, 2020, would provide gross income tax credit to essential employees working during the COVID-19 pandemic, including hospice workers.

New York

2019 NY A.B. 10857 (NS), introduced July 24, 2020, would establish a temporary state commission to study and investigate the effects of the COVID-19 pandemic response on deaths in nursing homes

Ohio

2019 OH H.B. 606 (NS), adopted September 14, 2020, grants civil immunity to a person who provides health care services for injury, death, or loss that was caused by the transmission of COVID-19 during the period of emergency declared by Executive Order 2020-01D.

Pennsylvania

• 2019 PA H.B. 2437 (NS), amended/substituted on June 10, 2020, the Emergency Declaration Data Transparency Act, would require long-term care nursing facilities, hospices, personal care homes, and assisted living residences to report, in relation to COVID-19, the number and results of care recipients and employees who have been tested and the number of deaths among recipients and employees, along with the total number of recipients who reside in the facility and the total number of employees; make available data showing the number of recipients and employees who have tested positive and who have died in each facility as a result of COVID-19.

• 2019 PA H.B. 2509 (NS), amended/substituted May 26, 2020, would establish the Long-Term Care Facility Personal Protective Equipment Reimbursement Grant Program, administered by the Department of Aging.

• 2019 PA H.B. 2534 (NS), introduced May 19, 2020, the Communicable Disease Reporting Act, providing for the disclosure of communicable diseases in long-term care, hospice, and certain other facilities during disaster emergencies.

• 2019 PA H.B. 2608 (NS), introduced June 23, 2020, providing for the establishment of a stockpile of a 12-month supply of personal protective equipment for use by facilities including hospices and long-term care nursing facilities.

• 2019 PA H.B. 2867 (NS), introduced September 15, 2020, would provide for long-term infectious disease control in certain health care facilities (including long-term care, assisted living, and hospice).

• 2020 PA S.B. 1279 (NS), introduced October 19, 2020, the Essential Family Caregiver Designation Act, would allow designation of a family caregiver to provide companionship in compassionate care situations, including end-of-life situations and during disaster emergencies.

Utah

2020 UT S.B. 3002 (NS), adopted April 22, 2020, provides limited immunity for health care, including the use of certain treatments, provided during a major public health emergency; amends the Utah Right to Try Act to permit the use of certain investigational drugs and devices during a major public health emergency; and creates limited immunity for health care providers who provide an investigational drug or device to a patient during a major public health emergency.

Vermont

2019 VT H.B. 950 (NS), adopted June 15, 2020, allowing remote witnesses for advance directives for a limited time in response to the COVID-19 pandemic.

Virginia

• 2020 VA S.B. 5034 (NS), introduced August 18, 2020, would provide that any person serving a sentence imposed upon a conviction for a felony offense, other than a Class 1 felony, who is terminally ill or permanently physically disabled is eligible for consideration by the Parole Board for conditional release. The bill also provides that any person serving such sentence (i) who is 65 years or age or older and has served at least five years of the sentence imposed or (ii) who is 60 years of age or older and has served at least 10 years of the sentenced imposed is eligible for consideration by the Parole Board for conditional release without the need to petition the Parole Board; establishes a four-level classification system for the awarding and calculation of earned sentence credits; and requires the calculation of earned sentence credits to apply retroactively to the entire sentence of any inmate who is confined in a state correctional facility and participating in the earned sentence credit system.

• 2020 VA H.B. 5041 (NS) and 2020 VA S.B. 5042 (NS), adopted October 21, 2020, requires the Board of Health to amend regulations governing nursing homes, certified nursing facilities and hospices to require that, during a public health emergency related to COVID-19, each nursing home, certified nursing facility, and hospice to establish a protocol to allow each patient to receive visits, consistent with guidance from the Centers for Disease Control and Prevention and as directed by the Centers for Medicare and Medicaid Services and the Board.

• 2020 VA H.B. 5059 (NS), adopted October 13, 2020, providing that a licensed hospice, home care organization, private provider, assisted living facility, or adult day care center that delivers care to or withholds care from a patient, resident, or person receiving services who is diagnosed as being or is believed to be infected with the COVID-19 virus shall not be liable for any injury or wrongful death of such patient, resident, or person receiving services arising from the delivery or withholding of care when the emergency and subsequent conditions caused by the emergency result in a lack of resources, attributable to the disaster, that render such hospice, home care organization, private provider, assisted living facility, or adult day care center unable to provide the level or manner of care that otherwise would have been required in the absence of the emergency and that resulted in the injury or wrongful death at issue.

• 2020 VA H.B. 5121 (NS), introduced August 24, 2020, and 2020 VA S.B. 5042 (NS), amended/substituted August 27, 2020, would require each nursing home, certified nursing facility, and hospice facility to allow every patient to receive visits, either virtually or in person, at least once per week from family or any person designated by the patient. If such visits are conducted virtually, each such facility shall provide access to equipment and staff support that (i) allows each patient the ability to schedule and receive no less than one virtual visit per week and (ii) provides both visual and sound technology allowing the patient to interact with persons outside the facility, unless the patient or power of attorney of the patient waives such rights to virtual visitation and such waiver is noted in the care plan for the patient. Any person visiting a patient in person may be required to comply with all reasonable requirements of such facility adopted to protect the health and safety of patients and staff of the facility. Each such facility shall publish on its website or provide written communication of its plan for providing virtual or in-person family visits.

• 2020 VA H.B. 5140 (NS), introduced August 26, 2020, would provide that during a declared public health emergency related to a communicable disease of public health threat, every hospital, nursing home, nursing facility, hospice, and assisted living facility shall allow visits from a patient's or resident's family members or any person designated by the patient when the patient has been diagnosed with a terminal condition or illness and the patient's death is expected to be imminent.

• 2020 VA S.B. 5018 (NS), adopted October 28, 2020, provides that any person serving a sentence imposed upon a conviction for a felony offense other than those enumerated in the bill as exceptions to eligibility and who is terminally ill, as defined in the bill, is eligible for consideration by the Parole Board for conditional release.

• 2020 VA S.B. 5034 (NS), adopted November 9, 2020, provides that any person serving a sentence imposed upon a conviction for a felony offense other than those enumerated as exceptions and who is terminally ill is eligible for consideration by the Parole Board for conditional release; establishes a four-level classification system for the awarding and calculation of earned sentence credits; specifies certain crimes that are subject to the maximum 4.5 earned sentence credits for each 30 days served that is permitted under current law.

• 2020 VA S.B. 5082 (NS), adopted October 13, 2020, provides that a licensed hospice, home care organization, private provider, assisted living facility, or adult day care center that delivers care to or withholds care from a patient, resident, or person receiving services who is diagnosed as being or is believed to be infected with the COVID-19 virus shall not be liable for any injury or wrongful death of such patient, resident, or person receiving services arising from the delivery or withholding of care when the emergency and subsequent conditions caused by the emergency result in a lack of resources, attributable to the disaster, that render such hospice, home care organization, private provider, assisted living facility, or adult day care center unable to provide the level or manner of care

that otherwise would have been required in the absence of the emergency and that resulted in the injury or wrongful death at issue. This bill incorporates 2020 VA S.B. 5023 (NS) and is identical to 2020 VA H.B. 5059 (NS).

Wisconsin

2019 WI A.B. 1038 (NS) and 2019 WI S.B. 932 (NS), introduced April 13, 2020, would, for the duration of the public health emergency relating to COVID-19, waive the requirement that a full autopsy be performed on a deceased inmate in the custody of the Department of Corrections; waive in-person requirements if the requirement may increase the public health risk; waives certain credentialing requirements for health care providers; waive life safety codes for hospices, nursing homes, hospitals and other facilities relating to fire alarm system maintenance and testing, automatic sprinkler and standpipe system inspection, testing, and maintenance, and inspection and maintenance of portable fire extinguishers; allowing home and community-based waiver services and administrative requirements to be provided remotely where possible and waiving certain other requirements; waiving cremation and autopsy requirement that coroner or medical examiner view corpse of person whose underlying cause of death is listed as COVID-19.

III. HOSPICE AND THE EVOLVING NATURE OF END-OF-LIFE CARE

Note: For the impact on hospice and end-of-life care wrought by the COVID-19 pandemic, see II. IMPACT OF COVID-19, above.

A report published in January 2019 by LeadingAge [FN35] discusses the development of hospice services over the past half century, current issues of quality assurance and financing, and recommendations for policy changes to make these services more accessible to people at the end of life. The publication describes the genesis of hospice services in the nonprofit sector and the growth of the sector following Medicare's expansion to cover hospice in the 1980s.

The analysis notes that hospice's prevalence has skyrocketed in recent years, with the number of providers nearly doubling since 2000, at about 4,200 in 2016. While the use of hospice services has grown, overall utilization remains low. About 28% of Medicare beneficiaries who used the benefit enrolled for fewer than seven days before death. And, there is wide variation from state to state: about 18% of Medicare beneficiaries used hospice in Alaska at the low end, compared to 59% in Arizona.

Between 2000 and 2016, the hospice patient population changed drastically. By 2016, hospice was serving more individuals residing in nursing homes and assisted living, in addition to its traditional home-based population, according to the report. In 2016, about half of all Medicare hospice beneficiaries died at home, while one-third died in a nursing home. Terminal conditions treated by the benefits have changed too. While the service was almost exclusively limited to cancer in the past, patients with dementia and heart disease are increasingly using it, too.

Produced in conjunction with LeadingAge Ohio and the National Partnership for Hospice Innovation, the report offers several suggestions to bolster use of hospice services:

• Ensuring that value-based insurance design under Medicare Advantage gives Medicare beneficiaries access to nonprofit, community-integrated hospice providers;

• Full information for Medicare beneficiaries and their families on care options when they are faced with advanced illness;

• Increased flexibility for care team composition in rural areas where healthcare workforce shortages are acute; and

• Expansion of telehealth options in hospice.

Researchers at Boston's Massachusetts General Hospital have determined that videos depicting the effects of dementia at life's final stages could help seniors with choosing options for end-of-life care, *McKnight's Long-Term Care News and Assisted Living* reported. [FN36] A study of 200 healthy seniors split into two groups showed that those who viewed a video presentation portraying advanced dementia were more likely to choose the option of comfort/palliative care rather than “care to prolong life at all costs” or “limited care to maintain physical function.” In the study, 86 percent of seniors participating in the video group chose the comfort/palliative care option.

As reported by *USA Today,* hospital ethics panels often serve as intermediaries between family members and healthcare personnel when end-of-life decisions must be faced in various hospital settings.“ [FN37] Often serving on a volunteer basis, ethicists are said to help when patients and their families must “make the choices of a lifetime.” As noted by *USA Today*, only 25 percent of the U.S. population has written, advance care directives determining treatment protocol at life's end. Others, it says, must make last-minute choices or let choices be made for them. And, says *USA Today*, “the sticking points are almost never cost or insurance,” even in the middle of the current health reform debate and rumors of so-called “death panels.” In some hospitals, such as the Rochester, Minn. Mayo Clinic, one physician becomes the contact person for the ethics team through whom the patient, family, and staff must communicate. This, said the clinic, helps eliminate “the blizzard of messages from a constantly shifting medical staff [that] left some families locked in indecision.”

A study undertaken by University of Michigan researchers has shown that a group of colostomy patients who were told they had “no hope for getting better reported greater levels of happiness since they had gotten on with their lives.” [FN38] Members of another control group who were told their colostomies would be reversed “believed their condition to be temporary [and] had a more difficult time adjusting to their new situation.” As documented by *McKnight's Long-Term Care News & Assisted Living*, physicians need to be “mindful of the dichotomy” of providing hope versus presenting an illness in more realistic terms. Otherwise, said Peter A. Ubel, M.D., who led the research, hope may be built up to the point that patients “put off living their lives.”

Improving and exercising proper and effective end-of-life care is beginning to be addressed at various levels. For example, a Web site created by doctors affiliated with the American Academy of Hospice and Palliative Medicine (AAHPM) and specializing in palliative care seeks to raise awareness of the roles of hospice care as well as palliative medicine in the management of terminal illness. [FN39] The Web site, PalliativeDoctors.org, provides an overview of end-of-life options and a clear definition of what palliative care is and what it is not. As documented by *The Medical News*, Gail Austin Cooney, MD., a palliative doctor and president of AAHPM, feels that myths and untruths about the practices of palliative and hospice care need to be dispelled. “There is enormous misunderstanding about palliative medicine,” said Dr. Cooney, “and tremendous fear associated with it.”

While Americans generally agree that discussing end-of-life care with their loved ones is important, a recent study conducted by Bestow [FN40] looked into the amount of interest shown by the various states. Wisconsin, New York, New Hampshire, South Dakota, and Ohio were found to be the five states that are *most* concerned about end-of-life issues. In contrast, Nevada, California, Wyoming, Utah, and Alaska are the five states that are least concerned.

A. CMS Rule Outlines Patient Rights; Requires Quality-of-Care Tracking

Patient rights concerning end-of-life treatment and hospice care are detailed in a Medicare Conditions of Participation (CoP) rule published by the Centers for Medicare & Medicaid Services (CMS) in 2008. [FN41] The revamped final rule?the first “overhaul” since 1983 of regulations governing the hospice industry?sets forth that patients who choose hospice or palliative care over curative treatment are entitled to such things as participation in their treatment plans; the right to effective pain management; the right to refuse treatment; and the right to select their own physicians. In addition to the new patient rights section, the final regulation also includes: a requirement that patient needs be initially assessed within 48 hours of electing the hospice benefit; a requirement that each hospice patient receive a full drug profile that examines issues ranging from the effectiveness of current drug therapies to potential drug interactions to drug side effects; a provision allowing a hospice to contract with another Medicare-certified hospice for nursing, medical social services and counseling services under extraordinary or other non-routine circumstances; and removal of a provision requiring an inpatient facility only providing respite care to have an RN on duty 24 hours per day. The new rule also requires that hospice care facilities implement a program for quality assessment as well as a system for improvement. [FN42] The CMS final rule, published in the June 5, 2008, *Federal Register*, [FN43] was effective Dec. 2, 2008.

B. End-of-Life Counseling by Physicians

The *New York Times* reported in 2009 that possible misconceptions had arisen over a provision in the House version of a new health reform bill (2009 FD H.B. 3200 (NS)) seeking to allow Medicare coverage of the advising of patients on life-sustaining treatment and end-of-life options by physicians. [FN44] Rep. G.K. Butterfield (D-N.C.), documented the *Times*, feels seniors are now worried that they may lose their Medicare benefits altogether or that “they will have to discuss plans for end-of-life care every five years.” In addition, conservative groups such as the Family Research Council have voiced concerns that the bill's end-of-life provision would place limitations on this type of care. House Republican leader, Rep. John Boehner (R-Ohio) was quoted by the *Times* as saying that inclusion of the provision in health reform legislation “may start us down a treacherous path toward government-encouraged euthanasia.”

The White House announced on January 5 that it would remove references to voluntary end-of-life counseling in rules for Medicare's new annual checkup. The decision is unlikely to have much impact on patients and doctors already discussing options for care in the last stages of life; voluntary end-of-life planning is already covered as part of the “Welcome to Medicare” doctor visit, available to seniors within the first year of joining the program. The original House version of the overhaul legislation sought to expand coverage, however, allowing for discussions every few years. The plan was dropped after Sarah Palin and other Republicans referred to it as “death panels” deciding the fate of vulnerable seniors, charges that were later defused by non-partisan fact checking groups. Administration spokesman Robert Gibbs said the administration still supports end-of-life planning, but is pulling the language because there wasn't enough chance for all sides to comment on the change.

Although federal rules require that hospital patients are informed of their right to articulate their wishes about being kept alive mechanically if there's no hope for a cure, many doctors and public health advocates think government should take a more direct role in encouraging people to plan ahead. Opponents counter that such decisions are highly personal, and government should stay out. They worry that explicitly including end-of-life counseling in Medicare rules could send an indirect message that people facing serious illness should be nudged toward hospice care, giving up on seeking a cure. [FN45]

End-of-life Discussions Improve Care Outcomes in Last Month of Life

While only a fraction of nursing home patients undertake end-of-life discussions, those patients were less likely to die in the hospital and more likely to appoint a surrogate to coordinate their care, according to a study published in *Age and Ageing*. [FN46] In a study of 674 residents in 78 nursing home facilities in France, researchers found that only about one fifth of the residents discussed end-of-life issues with their physicians. No end-of-life discussions whatsoever were held with a third of patients or their families. Patients who discussed three or more of six end-of-life topics with their physicians and caregivers in their last months of life stood less chance of dying in a hospital and had increased likelihood of appointing a surrogate or representative and a higher likelihood of withdrawing potentially futile life-prolonging treatments, the study found. The six end-of-life topics included talks about the course and prognosis of

a resident's disease, the approaching end of life, the possibility of stopping treatments, options for palliative care, psychological issues, and spiritual or existential problems.

End-of-life Planning Does Not Make Cancer Patients Hopeless or Anxious

For a small group of advanced cancer patients, using an online tool?called “Making Your Wishes Known: Planning Your Medical Future,” (MYWK)?for learning about end-of-life medical decisions and developing an advance directive document, did not lead to psychological distress, according to a new study. [FN47] “One thing we noticed is that many patients with advanced cancer had not had these conversations,” said lead author Dr. Michael J. Green of the humanities and medicine departments at Penn State College of Medicine in Hershey, Pennsylvania. He and his team set out to see if it was true that working through end of life planning took away cancer patients' hope or raised their anxiety levels.

MYWK includes education modules on common medical conditions that can result in decisional incapacity, as well as medical treatments often introduced in life or death situations. Patients can choose a spokesperson, prioritize values and goals, match treatment options with priorities, and generate a printable advance directive document articulating their wishes.

For the study, the researchers divided 200 advanced-stage cancer patients with anticipated life expectancy of two years or less into two groups. One engaged in advanced care planning with the online tool, while the other used only a state-approved advance directive form and American Hospital Association educational materials. Those who used the MYWK online tool spent an average of 70 minutes in their advance care planning, compared to 26 minutes in the comparison group. Neither group had a decrease in hope or an increase in hopelessness after their advance care planning sessions, according to results in the Journal of Pain and Symptom Management. Anxiety levels decreased slightly for the MYWK group and stayed the same for the comparison group. Knowledge of advance care planning and feelings of self-determination increased slightly for both groups.

Doctors who initiate these conversations can do a lot to decrease patient stress and anxiety, but many physicians are hesitant and are also pressed for time, he said. The MYWK decision aid was modeled on what a conversation with your doctor should look like, he said.

C. End-of-Life Care Differs Depending on Hospital

A report released by the Dartmouth Atlas of Health Care found that the care provided to patients at the end of their lives differs significantly based on the hospital. The lead author of the study, Dr. David Goodman, stated, “Unfortunately the care that patients get is much more about where they happen to be treated rather than care that follows their preferences.” Whereas some doctors prefer aggressive treatments, many other prefer hospice. The study suggests that more patients would choose hospice. However, this report and previous ones have been criticized. Some say that the care provided was intended to prolong life and that imminent death was not obvious. [FN48]

In 2011, researchers at Dartmouth College released a report showing that at the end of life, people with chronic diseases get more aggressive medical care in the New York area than any place else in the country. The study, which looked at federal data from 2007 (the most recent available), found that 46 percent of chronically ill patients in the Manhattan hospital region were being treated at hospitals?as opposed to at home, in hospices, or nursing homes?when they died. That rate was the highest in the country. Nationally, 28 percent of chronic patients were being treated at hospitals when they died. Dr. Elliott S. Fisher, a co-author of the study, said that some of the disparity might be driven by financial incentives for keeping patients in New York-area hospitals while neglecting the true wishes of the patients. Colleague Dr. David C. Goodman pointed out that Medicare generally paid better for hospital-based care, including procedures and specialists, than for palliative care or community-based medical services. [FN49]

D. Racial and Cultural Effects on End-of-Life Care Preferences

A study presented to the American Academy of Hospice and Palliative Medicine and the Hospice and Palliative Nurses Association in Orlando, Fla. pointed to stark differences in attitudes toward end-of-life and hospice care between blacks and whites. [FN50] The study cited three major reasons for the disparity: 1) blacks prefer curative measures rather than palliative care at the end of life; 2) hospice care may be less available and perceived to be less affordable to this segment of the population; and 3) spiritual issues involving the acceptance of suffering as a part of life play a role in such decisions. Moreover, the study showed that blacks maintain a mistrust of the U.S. health care system in general; historically, service providers have been looked upon as unwelcoming and unaffordable. The 2006 data collected by the study revealed that of all hospice patients in the U.S., only eight percent were black. However, blacks?shown to have a higher incidence of cancer and heart disease have the very end-of-life illnesses most often served by hospice care. The study suggested that making hospice care more available and acceptable to blacks may require approaches that combine cure-based care with pain-easing and comfort-providing alternatives.

In 2008, a two-day program addressing blacks' resistance to end-of-life care? the first of its kind in the Southwest?was hosted in Dallas by hospitals, hospices and other care providers. [FN51] Titled “A Progressive Palliative Care Educational Curriculum for the Care of African-Americans at Life's End,” the symposium sought to discuss cultural and spiritual issues, improve communication, and dispel some of the lingering distrust of the health care system.

Results of a study published in the January 2009 *Journal of the American Geriatrics Society* indicated that individuals who were black or of Asian descent enrolled less frequently in a hospice program than whites or Hispanics. [FN52] Findings showed that blacks'

enrollment in hospice was nine percent lower than whites' while that of Asians was 24 percent lower. Citing similar studies, *Reuters Health* reported that blacks were found to be “less open to hospice care” and preferred more “aggressive treatments” when confronting terminal illness. *Reuters* also said that “[l]ittle is known about Asian-American patients' views.”

According to research in 2010, white patients are more likely than black patients to have their end-of-life care preferences followed. According to the research, both black and white patients stated similar rates of end-of-life discussions. The research reflected a preference among black patients to have life-prolonging care at the end of life, but those preferences were not followed. For example, some black patients who had a Do Not Resuscitate order were still given life-prolonging treatment. One researcher summarized the findings by stating, “Although the reasons for our findings are not fully understood, white patients appear to have undefined advantages when it comes to receiving end-of-life care that reflects their values.” [FN53]

Blacks and Latinos are far less likely than whites to plan for end-of-life medical care, a Rutgers sociologist has found. Deborah Carr, a professor in the Department of Sociology, conducted a study of chronically ill older adults in New Jersey and found that only 59 percent of blacks and one-third of Latinos have discussed how much medical intervention they would want near death, compared to 85 percent of whites. Among whites, two-thirds have a living will, compared to just 25 percent of blacks and Hispanics. Carr studied 300 subjects aged 55 and older seeking care at two large medical centers in urban New Jersey. She published her findings in *Omega: the Journal of Death and Dying*. Carr said that both religious beliefs and cultural attitudes toward receiving support from family members accounted for the gap between white subjects and minorities. Older blacks are more likely to believe that God controls the time and circumstance of someone's death and that it's inappropriate to interfere. For Latinos, the starkest contrast involved entrusting one particular family member with durable power of attorney. Only four percent of Latinos chose a relative to voice decisions for the incapacitated patient. “The likely explanation is that if you grew up in a culture that's close-knit, you make decisions as a family unit, you're not going to choose one person,” she said. In both black and Latino families, she said, there is evidence that people are more likely to view caring for ill or aging members as the norm, whereas white subjects had a greater fear of “burdening” family with their illness. Additionally, according to Carr and other researchers, blacks' distrust of the U.S. health care system has been widely documented, and perpetuated by actual and perceived experiences of discriminatory or poor quality care. “If you don't trust doctors, you need to put down on paper what treatments you want or don't want at the end of life,” said Carr. She noted that health care reform could play a role. One proposed benefit of the Affordable Care Act is to cover a doctor-patient consultation session regarding end of life issues for all Medicare beneficiaries. [FN54]

Ethnicity Complicates Discussions of End-of-Life Care

The *Washington Post* reports on a new study finding that “difficulty discussing end-of-life medical treatments is complicated further when there are ethnic differences that can create subtle barriers between the doctor and patient.” [FN55] A survey of more than 1,000 medical professionals by researchers at Stanford University's Medical School found that virtually all of them encountered difficulties holding end-of-life discussions with their patients. The difficulty was magnified by cultural and ethnic differences that hindered discussion about end-of-life treatment, with 86 percent rating them as “challenging.” Asian physicians reported the most struggles (91.3%), followed by African American (85.3%), Caucasian (83.5%), and Latino doctors (79.3%), according to the study.

Miscommunication or a lack of communication arises for a variety of reasons. Sometimes it's because the physician isn't familiar with the religious or spiritual beliefs embraced by some families and hasn't been trained to understand them. In some cultures, for example, people believe that talking about death is an ill omen that speeds its likelihood, the study says. Other times, the barriers exist simply because of language differences, even when medical translators were brought in. That's because medical jargon is not always easily translated. Neither are common phrases such as “heroic measures.” The medical translators can also contribute to the distance between a provider and patient, making it harder to talk frankly about death.

Other hindrances to communication came about because of greater distrust of medical professionals among some ethnic groups because of the legacy of the Tuskegee experiments and less “health literacy,” or familiarity with health care procedures.

Black Patients Less Likely To Seek Hospice Care

While hospice use is increasing and patients in the U.S. are increasingly dying at home, researchers have found racial disparities in intensity of healthcare treatment at the end of life, including hospice use. [FN56] The objective of the study was to examine differences between Black and White patients in end-of-life care in a population sample with well-characterized causes of death. Researchers used data from the Reasons for Geographic and Racial Differences in Stroke (REGARDS) study, an ongoing population-based cohort study with enrollment between January 25, 2003, and October 3, 2007, with linkage to Medicare claims data. Racial and regional differences in end-of-life outcomes and in stroke mortality among 1212 participants who died in the years 2013 to 2015 were also studied.

The study looked at hospice use of three or more days in the last six months of life, as shown in Medicare claims files. Other outcomes included multiple hospitalizations, emergency department visits, and use of intensive procedures in the last six months of life. Cause of death was determined by clinicians using death certificates, proxy interviews, autopsy reports, and medical records.

The study found that Black decedents were less likely than White decedents to use hospice for three or more days (34.9% vs. 46.2%). Substantial racial differences in treatment intensity and service use were found among persons who died of cardiovascular disease but not among patients who died of cancer. In analyses adjusted for cause of death (dementia, cancer, cardiovascular disease, and other) and clinical and demographic variables, Black decedents were significantly less likely to use three or more days of hospice and were

more likely to have multiple emergency department visits and hospitalizations, and undergo intensive treatment in the last six months of life compared with White decedents.

E. Dementia Patients' Receipt of Hospice Care

An analysis of nursing home records in 2010 found that many dementia patients are seeking hospice care. The analysis also found that approximately 40% of nursing home residents also suffer from some level of dementia. The study's authors fear that “Medicare policymakers will see this as a reason to cut costs. . . . Initiatives focusing on reducing long hospice stays could disproportionately and adversely affect the timing of hospice referral for persons with dementia. It is critical that the creation of any new policy explicitly consider the challenges inherent in the time of hospice referral for nursing home residents dying with dementia.” [FN57]

According to researchers, many people who suffer from advanced dementia are not receiving hospice care because they cannot meet the admission criteria. Researchers claim that the admission criteria are flawed because the guidelines suggest that practitioners should wait until the resident has an estimated six months left to live. It is extremely difficult to make this determination in certain dementia cases. The researchers suggest that “instead of using life expectancy as the requirement for admission, hospice care for dementia patients should be offered based on the patient's and family's desire for comfort care.” In an attempt to improve the chances of dementia patients getting palliative care, the researchers developed a new method of determining how long a patient has left to live. The Advanced Dementia Prognostic Tool (ADEPT) looks at “body mass index, ability to perform tasks of daily living like self-feeding, bowel incontinence, shortness of breath and oral food intake” among other things. The study was published in the November 3, 2010 issue of the *Journal of the American Medical Association*. [FN58]

A new study finds that most people with dementia don't die in nursing homes after all, but are more likely to spend their final days at home. 1,500 elderly adults with dementia were studied by investigators from the Indiana University School of Medicine and the Regenstrief Institute as they transitioned through various care settings. Researchers found that while 74% of the dementia patients were placed in nursing homes after a hospitalization, they did not stay there. In fact, only 19% died in facilities, compared to 46% that died at home. Lead researcher Christopher Callahan, M.D., said this finding runs counter to a common belief that such residents typically die in facilities. He added that “a better understanding of the relationships between sites of care for older adults with dementia is fundamental to building better models of care for these vulnerable elders.” [FN59] Full findings were published on May 15, 2012, in the *Journal of the American Geriatrics Society*. [FN60]

F. Hospice Use Linked to Fewer Depressive Symptoms for Surviving Spouses

Spouses of patients receiving hospice for three or more days more frequently reported reduced depression symptoms, compared to surviving spouses of patients who did not receive hospice, according to a study led by researchers at the Icahn School of Medicine at Mount Sinai published in *JAMA Internal Medicine*. [FN61]

This is the first national study to examine depressive symptoms as an outcome for spouses of people with all types of serious illnesses that used hospice care, which is designed to improve quality of life as opposed to offering “curative” disease treatments. Until now, studies demonstrating the benefits of hospice use on caregivers have been largely limited to cancer patients and their families, but hospice use has increased among those with other life-limiting illnesses. Currently, 45% of terminally ill patients in the U.S. die while receiving hospice care ? an increase of more than 20% over the past decade. After matching the sample of hospice users to a similar group that did not receive hospice, the research team found that improvement in depressive symptoms was more common among those who had used hospice, a benefit that was even more pronounced a year after a spouse's death. It is unknown which specific aspects of hospice care are associated with improved symptoms for spouses.

Researchers analyzed data from 1,016 deceased patients and their surviving spouses using the Health and Retirement Study (HRS), a national sample of adults over age 50 linked to Medicare claims. Surviving spouses were then followed through bereavement up to two years after death. Hospice services included medical services, symptom management, spiritual counseling, social services, and bereavement counseling delivered by an interdisciplinary team of professionals for patients with a prognosis of six months or less to live and who agree to forego curative treatments.

G. Hospice Services at Home

A study published in the *Journal of Clinical Oncology* found that cancer patients with hospice services who died in their homes had an improved quality of life in the end than those who spent their final days in a hospital or ICU. The study also found that caregivers and family members who were with the dying patients experienced less stress and debilitating grief when the patient was at home with hospice services. [FN62]

Terminally ill cancer patients had a better quality of life when they could die at home and avoid intense life-prolonging measures, a 2012 study found. Nearly 400 cancer patients were asked about their treatment preferences and support structures, along with socio-demographic factors. After their loved ones' deaths, caregivers were interviewed and asked about the location of the death, physical and psychological distress, and treatment of the patient. Those who had positive experiences tended to have died at home, had pastoral care, and had a “therapeutic alliance with the physician.” Chemotherapy, feeding tube positioning, and high degrees of anxiety and depression contributed to negative feelings, researchers said. The feelings are something that sometimes can be modified by health care workers, researchers noted. Caregivers and physicians who remain engaged and “present” with dying patients “by inviting

and answering questions and by treating patients in a way that makes them feel that they matter as fellow human beings ? have the capacity to improve a dying patient's [quality of life]," researcher Holly G. Prigerson, Ph.D., said. [FN63]

Citing a recent CDC report that found that more persons die at home, a study reported in *JAMA* examined the changes in site of death, place of care, and health care transitions between 2000, 2005, and 2009. Researchers used a random 20% sample of fee-for-service Medicare beneficiaries, aged 66 years and older, who died in 2000, 2005, or 2009. Based on billing data, patients were classified as having a medical diagnosis of cancer, chronic obstructive pulmonary disease, or dementia in the last 180 days of life. Comparing 2000, 2005, and 2009, the results indicate that the proportion of deaths in acute care hospitals decreased from 32.6% to 26.9% to 24.6% in 2000, 2005, and 2009, respectively. However, intensive care unit (ICU) use in the last month of life increased from 24.3% to 26.3% to 29.2%. Hospice use at the time of death increased from 21.6% to 32.3% to 42.2%, with 28.4% using a hospice for 3 days or less in 2009. The researchers concluded that among Medicare beneficiaries who died in 2009 and 2005 compared with 2000, a lower proportion died in an acute care hospital, although both ICU use and the rate of health care transitions increased in the last month of life. In addition, the author states that the results confirm the CDC finding based on death certificate data that more persons aged 65 years and older are dying at home, but the rate of ICU use in the last month of life has increased, that 11.5% of 2009 decedents had 3 or more hospitalizations in the last 90 days of life, that hospice use increased, but 28.4% of those decedents used a hospice for 3 days or less in 2009. [FN64]

For those who are nearing the end of life dealing with constant flare-ups of various chronic illnesses, "pre-hospice" care can provide an alternative to hospitals and allow patients to remain at home. End-of-life care is a massive problem that costs the health care system billions and, according to *Kaiser Health News,* "has galvanized health providers, hospital administrators and policymakers to search for solutions." [FN65]

In San Diego, for example, a new program called "Transitions" is designed to give elderly patients the care they want, at home, and keep them out of the hospital. Social workers and nurses regularly visit patients in their homes to explain what they can expect in their final years, help them make end-of-life plans and teach them how to better manage their diseases. Physicians track their health and scrap unnecessary medications. Unlike hospice care, patients don't need to have a prognosis of six months or less, and they can continue getting curative treatment for their illnesses, not just for symptoms.

H. Written Agreements Between LTC Facilities and Hospices

Effective August 26, 2013, long-term care providers will need to draw up written agreements with their hospice care partners, according to a final rule released on June 27, 2013, by the CMS. [FN66] The regulation clarifies the details of each contract in an effort to "improve quality and consistency of care between hospices and LTC facilities in the provision of hospice care to LTC residents," according to the rule. To clarify the roles and responsibilities of each entity, the LTC facility and hospice provider must devise an agreement that specifies the following:

• Services to be provided by the hospice and a delineation of its responsibilities, including: providing medical direction and management of the patient; nursing; counseling; social work; medical supplies, durable medical equipment, and drugs necessary for the palliation of pain and symptoms.

• Hospice's responsibilities for determining the appropriate hospice plan of care

• Services the LTC facility will continue to provide, based on each resident's plan of care

• Communication process, including how the communications will be documented between the LTC facility and the hospice provider

• Notification by LTC facility of the hospice about a significant change in the resident's status; clinical complications that suggest a need to alter the plan of care; a need to transfer the resident from the facility for any condition; or the resident's death.

• Hospice's responsibility for determining the appropriate course of hospice care, including the determination to change the level of services provided.

• LTC facility's responsibility to furnish 24-hour room and board care and personal care needs in coordination with the hospice representative.

• LTC facility reporting of all alleged violations involving mistreatment, neglect, or verbal, mental, sexual, and physical abuse.

I. "Smart Technology" Use in Home Hospice

Early findings from a study of 319 families suggest that a "smart technology" system for home hospice symptom management and care helps both patients and caregivers. Use of an innovative, telephone-based symptom monitoring and coaching system during home hospice care led to significantly decreased patient symptoms in the final weeks of life. Essentially, the technology-enhanced communications between the caregiver and hospice nurse, providing caregivers with real-time solutions of "coaching tips," coauthor Bob Wong, PhD, said. Dr. Wong presented results of the study at a press briefing held in advance of the inaugural 2014 Palliative Care in Oncology Symposium. The study found that patients assigned to the symptom care intervention group reported significantly less symptom severity than those who received usual hospice care alone. Further, caregivers experienced 44% fewer days of moderate to

severe adverse symptoms, such as fatigue, anxiety, and sleep disturbance. Benefits for both patients and caregivers were observed as early as the first day after using the system, and continued throughout the hospice period. [FN67]

J. Hospice Use Does Not Increase Long-Stay Nursing Home Costs

According to a study conducted by University of Indiana Center for Aging Research and the Regenstrief Institute, use of hospice services does not increase care costs in the last six months of life for long-stay nursing home residents. Investigators found that avoidance of costly hospitalization and subsequent post-acute care in the nursing home appears to offset hospice services costs, even when hospice services are provided over a prolonged period of time.

The study looked at 2,510 long-stay nursing home decedents in Indiana, a third of whom received hospice services. Medicare costs were calculated for 2, 7, 14, 30, 90, and 180 days before death; Medicaid costs were calculated for dual-eligible beneficiaries. Total costs and costs for hospice, nursing home, and inpatient care are reported. The mean length of hospice was 103 days (median 34 days); hospice users were more likely to have cancer, a do-not-resuscitate order in place, greater cognitive impairment, and worse activity of daily living (ADL) function, and were less likely to have had a hospitalization in the year before death. In propensity score analyses, hospice users had lower total Medicare costs for all time periods up to and including 90 days before death. For dually eligible beneficiaries, overall costs and Medicare costs were significantly lower for hospice users up to 30 days before death. Medicaid costs were not different between the groups except for the 2-day time period. Age, race, or gender had no effect on the findings.

The study found few significant differences in clinical or demographic characteristics between long stay nursing home decedents who did and did not receive hospice services near the end of life. The exception was residents with a cancer diagnosis, who were more likely to receive hospice than those with other diagnoses, also true of hospice use by those not in nursing homes. Advanced dementia also was associated with increased hospice use.

The long-stay nursing home residents whose records were reviewed for this study were disproportionately poor, non-white and characterized by high health care costs?individuals often not included in healthcare utilization studies. [FN68]

K. Nursing Shortages

Due to “extraordinary circumstances,” CMS says hospice agencies hit by the ongoing nursing shortage can continue using contracted staff. Regulations typically require that “core services” provided by hospice agencies be carried out directly by hospice employees, except under “extraordinary circumstances.” The nursing shortage, which the Bureau of Labor Statistics forecasts will continue through 2024, has forced the CMS to allow hospice agencies to “allow hospice agencies to elect this exemption to contract for nurses if the agency can demonstrate that the nursing shortage is creating an extraordinary circumstance that prevents it from hiring an adequate number of nurses directly” according to a memo [FN69] sent to state survey agency directors on October 21.

L. Veterans

The Department of Veterans Affairs (VA), in 2009, began a major, four-year investment in improving the quality of end-of-life care for veterans. The Comprehensive End of Life Care Initiative increased the numbers of VA medical center inpatient hospice units and palliative care staff members as well as the amount of palliative care training, quality monitoring, and community outreach.

In a study reported in *Health Affairs* [FN70] researchers compared hospice use among more than 1.1 million male veterans, aged 65 and older, between 2007 and 2014, with more than 140,000 demographically similar Medicare beneficiaries not enrolled in VA healthcare. By 2011, they found that 44 percent of veterans who died in hospitals took their last breaths in hospice beds, compared to 30 percent in 2008. By 2012, 71 percent of veterans dying of cancer were enrolled in hospice. Additionally, after adjusting for age, race and ethnicity, diagnoses, nursing home use in the last year of life, census region, and urbanicity of a person's last residence, the researchers found a 6.9 to 7.9 percentage-point increase in hospice use over time for the veteran categories, compared to a 5.6 percentage-point increase for nonveterans (the relative increases were 20?42 percent and 16 percent, respectively).

Researchers concluded that the VA's substantial investment in palliative care appears to have resulted in greater hospice use by older male veterans enrolled in the VA, a critical step forward in caring for veterans with serious illnesses.

Use of Home Hospice Increasing

Recent research has found that rates of hospice utilization were higher among veterans than other Medicare decedents, with over half of veterans receiving care in the home. [FN71] The findings reflect a growing industry-wide trend toward community-based care. The study, from the U.S. Department of Veterans Affairs (VA) Home Based Primary Care (VA-HBPC), found rates of home hospice utilization among veterans increased from 2008 to 2016.

More than 60% of veterans died at home compared to less than 50% of non-veterans in community-based settings, according to authors Suzanne Gillespie, M.D., and Orna Intrator. Veterans were less likely to use end-of-life care in other settings, with approximately 11% dying in inpatient hospice units, 14% in hospitals, and 11% in nursing homes.

The VA began the Comprehensive End-of-Life Initiative in 2009 to improve the quality of end-of-life care among veterans and increase dying veterans' enrollment in hospice for care more aligned with their goals. The initiative has led to an increase of roughly 7?8% increase in hospice use among veterans. [FN72]

M. Nurses May Be Key to Improving the Quality of End-of-Life Care

A new study [FN73] from the University of Pennsylvania School of Nursing's Center for Health Outcomes and Policy Research (CHOPR) looked at the quality of end-of-life care in nearly 500 hospitals in the U.S., utilizing nearly 13,000 bedside nurses as informants of quality.

The majority of nurses (58%) rate their hospital's end of life care unfavorably. The most common quality problem cited by nurses (53%) is that patients often experience painful procedures that are not likely to change their clinical outcome. This finding is consistent with growing trends towards aggressive medical intervention in the final days of life, which is widely recognized as inappropriate for terminally ill individuals.

Further, over a third of nurses (37.7%) report being discouraged from discussing alternative care options with patients and their families. A similar percentage of nurses say they often disagree with their physician colleagues about end-of-life care decisions, and feel decisions are not made as a team.

'Even the best hospitals have significant room for improvement when it comes to providing better care for patients at the end of life' says lead-author Karen Lasater, PhD, RN, Assistant Professor of Nursing. “Hospitals are failing to capitalize on an already available cadre of skilled end-of-life care providers available for every patient in every hospital? registered nurses at the bedside.”

The study found that end-of-life care is best in hospitals characterized by effective nurse-physician teamwork, where authority is devolved to nurses to act in their areas of expertise, where nurses have manageable workloads, and where they are highly engaged in hospital decision-making.

'For patients and families, making health care decisions at the end of life is stressful. They want to be cared for by a team of providers that elicit and respect their care preferences. They want information about disease progression, symptom management, and the full array of care options. They want to be acknowledged as a whole person?with goals beyond prolonging life. This is at the heart of nurses' work,' says Lasater.

N. OIG Report Cites Hospice Quality Problems

According to a recent audit [FN74] by the Department of Health and Human Services' Office of Inspector General, a majority of hospices recently had at least one deficiency in the quality of care they provide. The OIG based the study on an analysis of CMS's deficiency and complaint data from 2012 through 2016. It analyzed data from State agencies and accrediting organizations and also reviewed the survey reports from State agencies for a purposive sample of 50 serious deficiencies. The OIG found that over 80 percent of the hospices had at least one deficiency. The most common types of deficiencies involved poor care planning, mismanagement of aide services, and inadequate assessments of beneficiaries.

The report also recommended that CMS should implement existing OIG recommendations to strengthen the survey process, establish additional enforcement remedies, and provide more information to beneficiaries and their caregivers. In addition, it recommended that CMS:

• expand the deficiency data that accrediting organizations report to CMS and use these data to strengthen its oversight of hospices;

• take the steps necessary to seek statutory authority to include information from accrediting organizations on Hospice Compare (CMS's website that contains limited information about individual hospices);

• include on Hospice Compare the survey reports from State agencies;

• include on Hospice Compare the survey reports from accrediting organizations, once authority is obtained;

• educate hospices about common deficiencies and those that pose particular risks to beneficiaries; and

• increase oversight of hospices with a history of serious deficiencies.

CMS either concurred or partially concurred with all the recommendations except the third.

To address the issues described in the OIG reports, the National Association for Home Care & Hospice (NAHC) has made recommendations to CMS and other stakeholders. [FN75] NAHC recommends increasing the frequency of surveys for hospices that have a history of serious deficiencies, including unannounced spot checks, making state agency and accreditation organization reports publicly available, and additional action to improve CMS' process for capturing and responding to patient complaints and to strengthen the effectiveness of the survey process. NAHC also called for CMS to evaluate the consistency of state agency surveyor and accreditation organization surveyor actions that pertain to Medicare Conditions of Participation, as well as CMS regional office interpretations and applications. They also advocated annual audits to ensue survey accuracy.

O. Telehealth Proposal

Hospice physicians would be able to recertify patients via telehealth systems under legislation proposed by a bipartisan group of congressional legislators have introduced corresponding bills in the House and the Senate (2019 CONG US HR 4932 and 2019 CONG US S 2741, introduced October 30, 2019). Currently, Medicare conditions of participation require hospice physicians to meet with patients face-to-face, as part of the recertification process that initiates after the patient has been in hospice for 180 days. Beneficiaries

can receive telehealth services only if they are in certain rural areas and at certain clinical sites. Given the restrictions, utilization of telehealth is low among Medicare-certified organizations, and only 0.25% of Medicare beneficiaries use telehealth services, according to the U.S. Centers for Medicare & Medicaid Services.

The “CONNECT for Health Act” would expand the use of telehealth throughout the Medicare system across multiple health care settings. As put forth by Sens. Brian Schatz (D-Hawaii) and Roger Wicker (R-Miss.), and Reps. Cindy Hyde-Smith (R-Miss.), Ben Cardin (D-Md.) and Peter Welch (D-Vermont), hospices would still be required to comply with documentation rules for recertifications.

If enacted, recertification via telehealth could have a significant business impact on hospice operations. Expansion of telehealth is expected to have the most impact on patients in remote and rural areas. In addition, hospices can leverage the technology in a variety of ways, by allowing patients and families improved access to clinicians and enabling staff to consult specialists or physicians while in the patient's home. Clinicians also use the systems to stay in touch with patients during weather emergencies or when road conditions are slowing or impeding travel.

Telehealth technology for hospice services receives wide support from the industry. “The hospices would have to pay for the telehealth technology themselves, but once that was set up, allowing the actual physicians and nurse practitioners to devote more time to working in the organization in other ways would have a great impact,” Mollie Gurian, director of hospice, palliative and home health policy for LeadingAge. “We have heard from some programs that the amount that they spend on full time employees doing these recertifications is quite large. It could be as much as half a million dollars just for the professionals to do face-to-face recertifications. That would be a huge impact, as well as a way to more fully test telehealth in the hospice benefit.” [FN76]

P. Where People Die: Study

Analysis of data from the Centers for Disease Control and Prevention and the National Center for Health Statistics finds that more people are dying at home and in hospice than in nursing facilities and hospitals. Authored by Sara H. Cross, of Duke University Sanford School of Public Policy, and Haider J. Warraich, of Veterans Affairs Boston Healthcare System, the study looked at natural deaths in the United States from 2003 through 2017. [FN77] Between 2003 and 2017, there were nearly 35.2 million natural deaths, according to the study. Most were attributed to cardiovascular disease (29.3%), followed by cancer (24.5%), respiratory disease (10.5%), dementia (7.9%), and stroke (5.9%).

Between 2003 and 2017, deaths occurring in hospitals decreased from 39.7% in 2003 to 29.8% in 2017; deaths at nursing facilities decreased from 23.6% to 20.8%. Whereas the number of deaths at home increased from 23.8% in 2003 to 30.7% in 2017; deaths at hospice facilities increased from 0.2% to 8.3%. These trends were seen across all disease groups. Home has surpassed the hospital as the most common place of death in the U.S. for the first time since the early 20th century, according to co-author Warraich.

The study also found that younger patients, female patients, and racial and ethnic minorities had lower odds of death at home than did older patients, male patients, and white patients. Patients with cancer had the greatest odds of death at home and death at a hospice facility and the lowest odds of death at a nursing facility relative to other conditions. Patients with dementia had the greatest odds of death at a nursing facility, and patients with respiratory disease had the greatest odds of death at a hospital. Patients with stroke had the lowest odds of death at home, and patients with cardiovascular disease had the lowest odds of death at a hospice facility relative to other conditions.

Q. Recent Legislative Activity

Federal

• 2019 CONG US S 2262, introduced July 25, 2019, the “Expedited Disability Insurance Payments for Terminally Ill Individuals Act of 2019” would provide for phased-in payment of Social Security Disability Insurance payments during the waiting period for individuals with a terminal illness.

• 2019 CONG US S 4945, introduced December 2, 2020, the “Compassionate Care Act,” to improve end-of-life care, would provide for a national public education campaign on advance care planning, development of core end-of-life quality measures across provider settings; permanent extension of telehealth to conduct face-to-face recertification of hospice eligibility; and studies on advance directives.

• 2019 CONG US HR 5582, introduced January 10, 2020, and 2019 CONG US S 3138, introduced December 19, 2019, would require hospitals and certain other participating providers under Medicaid or the Children's Health Insurance Program to disclose the provider's policy on parental consent for the provision, withdrawal, or denial of life-sustaining treatment for minors, and for other purposes.

Connecticut

• 2020 CT H.B. 5095 (NS), introduced February 11, 2020, would provide aid in dying to terminally ill patients.

• 2020 CT H.B. 5420 (NS), introduced March 2, 2020, would provide aid in dying to terminally ill patients.

District of Columbia

2019 DC L.B. 733 (NS), adopted April 10, 2020, allows for the compassionate release of individuals convicted of felony offenses if the court determines the defendant is not a danger to the safety of any other person or the community the defendant has a terminal illness.

Florida

• 2020 FL H.B. 177 (NS), adopted June 9, 2020, Prescription Drug Donation Repository Program, relating to the prescription drug donation repository program, providing criteria and conditions for donation of prescription drugs and supplies from certain authorized entities (including hospices) for dispensing to eligible patients.

• 2020 FL H.B. 837 (NS), introduced January 14, 2020, would provide for the release under the conditional medical release program of an inmate determined to be terminally ill.

• 2020 FL S.B. 556 (NS), introduced January 14, 2020, would establish the conditional medical release program within the Department of Corrections requiring any inmate who is terminally ill or meets other criteria to be considered for conditional medical release; providing for victim notification in certain circumstances; providing that an inmate who is approved for conditional medical release must be released from the department in a reasonable amount of time; providing that a medical release remains in the care, custody, supervision, and control of the department and is eligible to earn or lose gain-time, etc.

Georgia

• 2019 GA H.B. 586 (NS), introduced March 8, 2019, provides for disposal of unused prescribed controlled substances for hospice patients by hospice staff.

• 2019 GA H.B. 983 (NS), adopted August 3, 2020, relating to the Sexual Offender Registration Review Board, to revise the information required to be provided by sexual offenders when they register; to allow a sexual offender who is in a state or privately operated hospice facility, skilled nursing home, or residential health care facility, with the approval of the sheriff of the county where such sexual offender resides, to satisfy the annual registration requirements by registering at any time during the sexual offender's month of birth; to remove the requirement that a sexual offender who resides in a state or privately operated hospice facility, skilled nursing home, or residential health care facility, with the approval of the sheriff of the county where such sexual offender resides, be fingerprinted; to repeal the registration fee collection requirements.

Hawaii

• 2019 HI H.B. 665 (NS), amended/substituted April 25, 2019, specifies that a health care provider shall not be required to consult the electronic prescription accountability system for patients when the prescription will be directly administered under the supervision of a health care provider, provided that the system is consulted when the patients are initially admitted at a hospital, for patients in post-operative care with a prescription limited to a three-day supply, or for patients with a terminal disease receiving hospice or other palliative care.

• 2019 HI S.B. 2582 (NS), introduced January 17, 2020, and 2019 HI H.B. 2451 (NS), introduced January 23, 2020, would authorize advanced practice registered nurses, in addition to physicians, to practice medical aid in dying in accordance with their scope of practice and prescribing authority; would reduce the mandatory waiting period between oral requests from twenty days to fifteen days; and would waive the mandatory waiting period for those terminally ill individuals not expected to survive the mandatory waiting period.

Illinois

2019 IL H.R. 691 (NS), introduced January 29, 2020, states the belief that Illinois must be proactive in educating, empowering, and advocating for those at the end of life, and urges Congress to enact legislation that would encourage Medicare and Medicaid to take meaningful steps toward identifying and educating vulnerable populations that are nearing the end of life.

Indiana

2020 IN H.B. 1020 (NS), introduced January 7, 2020, would allow individuals with a terminal illness who meet certain requirements to make a request to an attending physician for medication that the individual may self-administer to end the individual's life; specify requirements a physician must meet in order to prescribe the medication to a patient; prohibit an insurer from denying payment of benefits under a life insurance policy based upon a suicide clause in the life insurance policy if the death of the insured individual is the result of medical aid in dying; establish a Level 1 felony if a person: (1) without authorization of the patient, willfully alters, forges, conceals, or destroys a request for medication or a rescission of a request for medication with the intent or effect of causing the individual's death; or (2) knowingly or intentionally coerces or exerts undue influence on an individual to request medication to end the individual's life or to destroy a rescission of a request for medication to end the individual's life.

Iowa

2019 IA H.B. 19 (NS), introduced January 22, 2019, and 2019 IA S.S.B. 1012 (NS), introduced January 15, 2019, would add correctional institutions under the control of the Department of Corrections, to the list of places where a nurse may make a pronouncement of death for a patient whose death is anticipated. Currently, nurses working in these institutions must request a doctor to make pronouncements of death.

Louisiana

• 2020 LA H.B. 43 (NS), adopted October 28, 2020, relative to rights of nursing home residents and residents of adult residential care provider facilities, with special consideration given to residents receiving end-of-life care.

• 2020 LA H.R. 47 (NS), adopted June 1, 2020, requests the Louisiana Department of Health to amend its administrative rule regarding the geographic location of a hospice provider within a fifty-mile radius of the hospice proposed geographic location.

• 2020 LA S.B. 385 (NS), introduced March 9, 2020, relative to medical parole eligibility for prisoners who are terminally ill or permanently disabled.

Minnesota

2019 MN H.F. 2340 (NS), introduced March 11, 2019, and 2019 MN S.F. 2195 (NS), introduced March 7, 2019, would provide funding for perinatal hospice grants.

Mississippi

2020 MS H.B. 1520 (NS), adopted June 25, 2020, allows hospice medical directors to prescribe controlled substances for pain for terminally ill patients without an in-person visit.

Missouri

2020 MO H.B. 1773 (NS), introduced January 8, 2020, would provide for the registration and compliance requirements of end-of-life care homes.

New Jersey

• 2020 NJ A.B. 576 (NS), introduced January 14, 2020, would make it a crime of the first degree to coerce a patient to request medication pursuant to the 'Medical Aid in Dying for the Terminally Ill Act' or to forge a patient's request for such medication.

• 2020 NJ A.B. 577 (NS), introduced January 14, 2020, would repeal the 'Medical Aid in Dying for the Terminally Ill Act.'

• 2020 NJ A.B. 2648 (NS), introduced February 13, 2020, would establish a Medicaid demonstration project to cover room and board services for certain terminally ill patients in the home or other non-institutional setting.

• 2018 NJ A.B. 5667 (NS), adopted January 21, 2020, "Charlie's Law," requires pharmacy practice sites and hospice programs to furnish patients with information and means to safely dispose of unused prescription drugs and medications.

• 2020 NJ A.B. 830 (NS) and 2020 NJ S.B. 361 (NS), introduced January 14, 2020, would provide Medicaid coverage for certain home visitation program services, including hospice services.

• 2020 NJ S.B. 1894 (NS), introduced on February 24, 2020, 'Linnette Lebron's Law'; would modify procedures for marriage or civil union where a party is terminally ill.

• 2020 NJ S.B. 2086 (NS), introduced March 16, 2020, would establish a Medicaid demonstration project to cover room and board services for certain terminally ill patients in the home or other non-institutional setting.

• 2020 NJ S.B. 2594 (NS), introduced June 22, 2020, would establish a compassionate release program for inmates diagnosed with a terminal condition, disease, or syndrome.

• 2018 NJ S.B. 3116 (NS), adopted January 21, 2020, requires assisted living facilities, dementia care homes, nursing homes, assisted living residences, comprehensive personal care homes, residential health care facilities, hospitals, and long-term care facilities to undertake end-of-life planning and training.

New York

• 2019 NY A.B. 1124 (NS), adopted December 12, 2019, provides that health care decisions regarding routine medical treatment for adult patients without surrogates are not required to be reviewed by an ethics committee.

• 2019 NY A.B. 6768 (NS), introduced March 19, 2019, relating to home care and hospice worker shortage areas and disciplines.

• 2019 NY A.B. 6902 (NS), introduced March 25, 2019, would direct the commissioner of labor to conduct a labor market study of the home care and hospice workforce; and establish a temporary labor task force for home care and hospice services and occupations.

• 2019 NY A.B. 10264 (NS), introduced April 8, 2020, relating to requiring veterans' homes to offer hospice care.

• 2019 NY S.B. 230 (NS), introduced January 9, 2019, would authorize hospice residences to care for up to 25 patients in New York City.

• 2019 NY S.B. 1359 (NS), introduced January 14, 2019, would direct the commissioner of labor to conduct a labor market study of the home care and hospice workforce, and establish a temporary labor task force for home care and hospice services and occupations.

• 2019 NY S.B. 6356 (NS), introduced June 6, 2019, relating to decisions about routine medical treatment for hospice patients without a surrogate decision maker.

North Carolina

2019 NC H.B. 126 (NS), engrossed July 24, 2019, would amend certificate of need laws for health service facilities, including hospice offices, inpatient facilities, and residential care facilities.

Ohio

2019 OH H.B. 426 (NS), introduced November 26, 2019, would establish requirements for the regulation of hospice transport vehicles and to modify certain laws governing ambulances and other medical-related vehicles.

Oklahoma

2019 OK H.B. 3464 (NS), introduced February 3, 2020, relating to the 'Oklahoma Hospice Training Act.'

Pennsylvania

• 2019 PA H.B. 1058 (NS), introduced April 5, 2019, would require that information on the option of perinatal hospice care be given to a woman after diagnosis of a life limiting condition, and imposing penalties.

• 2019 PA H.B. 1919 (NS), introduced on March 4, 2020, would amend the Hospice and Home Health Prescription Medication Disposal Act, further providing for disposal of unused prescription medication.

• 2019 PA H.B. 2292 (NS), introduced February 18, 2020, would establish generator requirements for hospices, long-term care nursing facilities, assisted living residences, nursing homes, and personal care homes.

• 2019 PA H.B. 2516 (NS), introduced May 13, 2020, would establish the Nurse and Health Care Worker Loan Forgiveness Program and provide for the powers and duties of the Pennsylvania Higher Education Assistance Agency.

Utah

2020 UT H.B. 93 (NS), introduced January 27, 2020, the End of Life Options Act, would establish a procedure for an individual with a terminal disease to obtain a prescription to end the individual's life; designate when an individual may make a request for aid-in-dying medication; establish attending physician responsibilities; require a consulting physician confirmation, informed decision, written and oral requests and the ability to rescind the request and any time, waiting periods, and that the patient is a resident of the state; provide for a counseling referral when needed; encourage family notification; include documentation and reporting requirements; establish the effect of the decision to utilize aid-in-dying medication on an individual's wills, contracts, and insurance and annuity contracts; provide a uniform form for a patient's written request.

Virginia

• 2020 VA H.B. 471 (NS) and 2020 VA S.B. 540 (NS), introduced January 8, 2020, would require the director of every hospice organization and heads of other health care organizations to report to the Department of Health Professions any information of which they may become aware in their professional capacity that they have determined, in good faith, after investigation, review, or consultation, if and as needed, with the appropriate internal boards or committees authorized to impose disciplinary action on a health professional, indicates that there is a reasonable probability that such health professional may have engaged in unethical, fraudulent, or unprofessional conduct.

• 2019 VT H.B. 611 (NS), adopted October 5, 2020, establishing an Older Vermonters Act that provides a system of services, supports, and protections for Vermont residents 60 years of age or older, including hospice services; establishing annual inflationary increases to Medicaid reimbursement rates for home- and community-based service providers.

• 2020 VA H.B. 782 (NS) and 2020 VA S.B. 493 (NS), introduced January 8, 2020, would provide for the conditional release of geriatric, terminally ill, or permanently physically disabled prisoners serving a sentence imposed upon a conviction for a felony offense, other than a Class 1 felony.

• 2020 VA H.B. 5053 (NS) and 2020 VA S.B. 5018, introduced August 18, 2020, would provide that any person serving a sentence imposed upon a conviction for a felony offense, other than a Class 1 felony, who is terminally ill or permanently physically disabled is eligible for consideration by the Parole Board for conditional release. The bill also provides that any person serving such sentence (i) who is 65 years of age or older and has served at least five years of the sentence imposed or (ii) who is 60 years of age or older and has served at least 10 years of the sentenced imposed is eligible for consideration by the Parole Board for conditional release without the need to petition the Parole Board.

West Virginia

2019 WV H.B. 2825 (NS), introduced February 1, 2019, would create a workgroup to review the hospice need standards in the state.

IV. COSTS AND FUNDING OF END-OF-LIFE CARE

A. Medicare Funding

Currently, the Medicare hospice benefit covers the costs of palliative care for an individual who is terminally ill, in the individual's home, or in a nursing facility. Medicare does not have a long-term custodial nursing facility benefit, so that if an individual elects the Medicare hospice benefit in a nursing facility, the individual's room and board are not covered by Medicare and the individual or a third-party payor must pay for the costs of the room and board.

For those individuals who are dually eligible for Medicare and Medicaid who elect the Medicare hospice benefit, Medicare is financially responsible for the hospice care and the Medicaid program is the third-party payor responsible for the nursing facility room and board expense. For the nursing facility room and board care, the Medicaid program must provide for payment in an amount equal to at least 95 percent of the Medicaid daily nursing facility rate (the rate the state Medicaid program pays for nursing facility services furnished to an individual who has not elected to receive hospice care). Historically, the Medicaid program has paid the hospice provider for the nursing facility room and board expenses of dually eligible individuals who elect the hospice benefit, and the hospice provider has then passed through this payment to the nursing facility.

On July 31, 2020, CMS issued a final rule updating FY 2021 Medicare payment rates and the wage index for hospices serving Medicare beneficiaries. [FN78] In recognition of the significant impact of the COVID-19 public health emergency, and limited capacity of health care providers to review and provide comment on extensive proposals, CMS has limited annual hospice rulemaking required by statute to essential policies, including Medicare payment to hospices, as well as policies that reduce provider burden and may help providers in the COVID-19 response.

The final rule updates the hospice payment rates and cap amount for FY 2021, finalizing the adoption of the revised Office of Management and Budget statistical area delineations and applying a 5 percent cap on wage index decreases from FY 2020 to FY 2021.

For FY 2021, the hospice payment update is 2.4 percent ($540 million), a result of the 2.4 percent market basket percentage increase reduced by a 0.0 percentage point multifactor productivity adjustment. Hospices that fail to meet quality reporting requirements receive a 2 percentage point reduction to the annual market basket percentage increase for the year. The hospice payment system includes a statutory aggregate cap. The aggregate cap limits the overall payments made to a hospice annually. The final hospice cap amount for the FY 2021 cap year is $30,683.93, which is equal to the FY 2020 cap amount ($29,964.78) updated by the final FY 2021 hospice payment update percentage of 2.4 percent.

Finally, CMS is providing links to updated examples of the hospice election statement and the hospice election statement addendum that reflect the changes finalized in the FY 2020 hospice final rule, in order to assist hospices in understanding the content requirements for the hospice election statement and addendum, effective October 1, 2020. These requirements were finalized in order to increase coverage transparency for beneficiaries electing the Medicare hospice benefit.

In 2021, hospice and palliative care will be offered by 53 Medicare Advantage plans in 2021 through the value-based insurance design (VBID) model, according to CMS. Payers and hospice providers will have the option to participate in a demonstration project in 2021 (referred to as the ‘Medicare Advantage hospice carve-in’), to test the inclusion of hospice in VBID. The carve-in will begin at a time when Medicare Advantage premiums have dropped significantly, despite expanding benefits, even as the number of beneficiaries increases nationwide. [FN79]

Hospice Regulations Text Changes Due to the Bipartisan Budget Act of 2018: Section 51006 of the Bipartisan Budget Act of 2018 amended section 1861(dd)(3)(B) of the Social Security Act such that, effective January 1, 2019, physician assistants are recognized as attending physicians for Medicare hospice beneficiaries. This statutory change expands the definition of a hospice attending physician to include physician assistants in addition to physicians and nurse practitioners. We are finalizing changes to the hospice regulations to reflect that change.

A new Medicare hospice manual update includes instructions for which principal diagnosis codes are acceptable, and clarifies which codes should be used for services in a skilled versus non-skilled nursing facility. The changes go into effect October 1, 2014, CMS stated in a Medicare Learning Network memorandum sent on August 29. [FN80] A hospice claim should list a principal diagnosis “most contributory” to the patient's terminal prognosis, the memo states. It identifies several ICD-9 and ICD-10 codes that are not acceptable, including codes for “adult failure to thrive.” A number of dementia-related codes are not acceptable, but some that are listed under “Diseases of the Nervous System” are allowed in certain situations, according to the new instructions. Newly required time frames for submitting information to Medicare Administrative Contractors (MACs) are also included. When a beneficiary elects hospice coverage, a notice-of-election (NOE) is to be sent to and accepted by a MAC within five business days. If an NOE is not filed in a timely manner, the non-covered days are not to be billed to the beneficiary but will be a provider liability, the memo specifies. It also describes allowable exceptions to the five-day timeframe, such as if a natural disaster occurs.

CMS launched the Medicare Care Choices Model on March 18, 2014, providing choices to clinicians and patients for both curative and palliative care. Under the initiative, eligible Medicare beneficiaries with advanced cancers, chronic obstructive pulmonary disease, congestive heart failure, and HIV/AIDS may receive palliative care services from certain hospice providers while concurrently receiving services provided by their curative care providers. Currently, Medicare beneficiaries are required to forgo curative care in order to receive access to palliative care services offered by hospices. According to the CMS, the primary goal of the Medicare Care Choices Model is to test whether beneficiaries who meet Medicare hospice eligibility requirements would elect hospice if they could continue to seek curative services.

The Medicare Care Choices Model is mandated by the Affordable Care Act. “This initiative represents a fundamental change in the way health care is delivered,” said Sen. Ron Wyden (D-Or.), who authored the provisions that established the model. “Patients and their

families should have every choice available to them when faced with life-threatening illness. Allowing Medicare coverage to continue while under hospice care means that patients no longer have to make a false choice between hospice and curative care." [FN81]

Quality Reporting

In a final rule published by CMS in the *Federal Register* on August 4, 2011, [FN82] hospices are called upon to begin reporting on the quality of care received by Medicare patients. The final rule also implements Affordable Care Act requirements, including a hospice quality reporting program, and clarifies previously adopted policies on hospice face-to-face certifications, said Jonathan Blum, deputy administrator and director of CMS' Center for Medicare. Additionally, the final rule also revises how CMS calculates each hospice's yearly aggregate cap. Federal law requires that CMS impose a limit on the aggregate Medicare payments a hospice provider receives annually. CMS calculates each hospice's aggregate cap by multiplying the number of patients served by the hospice in a cap year by a cap amount. Medicare payments made to a hospice during the cap year that exceed the hospice's aggregate cap must be refunded to Medicare. In this final rule, CMS:

• Changes the way it counts hospice patients for the 2012 cap accounting year and beyond. This rule also finalizes that the new counting method be applied to past cap years in certain instances.

• Allows hospice providers who do not want a change in their patient counting method to elect to continue using the current method.

• Allows any hospice physician to perform the face-to-face encounter regardless of whether that same physician recertifies the patient's terminal illness and composes the recertification narrative.

• Implements a hospice quality reporting program, which includes a timeframe for reporting, as required by section 3004 of the Affordable Care Act. The measures that are being adopted in this final rule for the FY 2014 program are one measure endorsed by the National Quality Forum related to pain management and one structural measure that assesses whether a hospice administers a Quality Assessment and Performance Improvement (QAPI) program that contains at least three indicators related to patient care.

In 2017, CMS updated the hospice quality reporting requirements. In a final rule, CMS specifies public reporting measures derived from the CAHPS? Hospice Survey, and provides an update on the Hospice Quality Reporting Program, as mandated by ? 3004(c) of the Affordable Care Act. In accordance with section 1814(i)(5)(A) of the Act, hospices that fail to meet quality reporting requirements receive a 2.0 annual percentage point reduction to their payments. The rule finalizes eight measures from CAHPS Hospice Survey data already submitted by hospices. The rule also finalizes the extension or exception for quality reporting purposes from 30 calendar days to 90 calendar days after the date that an extraordinary circumstance occurred, and describes plans to publicly display quality measure data via Hospice Compare in August 2017. Additionally, this rule outlines policies and procedures associated with the public reporting of the quality measures used in the hospice program. The rule was published in the **Federal Register** on August 4, 2017. [FN83]

Vulnerabilities in Medicare Hospice Program

In a recent report, [FN84] the Office of the Inspector General (OIG) for the U.S. Department of Health and Human Services identified a number of vulnerabilities in the Medicare hospice program.

Use of hospice care has grown steadily over the past decade, with Medicare paying $16.7 billion for care in 2016, providing care to 1.4 million beneficiaries. Under the program, beneficiaries forgo curative care for the terminal illness and instead receive palliative care. Care may be provided in a variety of settings, including the home, nursing facility, hospital, or hospice inpatient unit. There are four levels of care; the most common is routine home care. Within each level of care, Medicare pays hospices for each day a beneficiary is in care, regardless of the quantity or quality of services.

The OIG found that hospices do not always provide needed services to beneficiaries and sometimes provide poor quality care. Unable to effectively manage symptoms in some cases, beneficiaries were left in unnecessary pain for several days. The OIG also found that hospices' inappropriate billing costs Medicare hundreds of millions of dollars, including billing for an expensive level of care when not needed. The OIG also found fraud schemes involving enrolling beneficiaries who are not eligible for hospice care and billing for services never provided.

Additionally, according to the report, the current payment system creates incentives for hospices to minimize their services and seek beneficiaries who have uncomplicated needs: within each level of care, a hospice is paid for every day a beneficiary is in its care, regardless of the quantity or quality of services provided.

The OIG recommends that the Centers for Medicare & Medicaid Services (CMS) implement 15 specific actions, relating to 7 areas for improvement. Key recommendations include:

• Survey process by CMS should be strengthened, to better ensure that hospices provide beneficiaries with needed services and quality care.

• Statutory authority to establish additional remedies for hospices with poor performance should be sought by CMS.

• Additional information on hospices, including complaint investigations, should be developed and disseminated by CMS, to help beneficiaries and their families and caregivers make informed choices about hospice care.

• CMS should educate beneficiaries and their families and caregivers about the hospice benefit, working with its partners to make available consumer-friendly information.

• Physician involvement and accountability to ensure that beneficiaries get appropriate care.

• To reduce inappropriate billing, CMS should strengthen oversight of hospices. This includes analyzing claims data to identify hospices that engage in practices that raise concerns.

• Payment should be tied to beneficiary care needs and quality of care to ensure that services rendered adequately serve beneficiaries' needs.

In response to a draft report, CMS concurred with 6 of 16 recommendations for specific actions, did not concur with 9, and neither concurred nor nonconcurred with one.

Hospice Utilization Studies

On October 10, 2016, CMS released the Hospice Utilization and Payment Public Use File (Hospice PUF), [FN85] providing information on services provided to Medicare beneficiaries by hospice providers. The agency also released an update to the Market Saturation and Utilization Data Tool, [FN86] to include information on hospice services.

The Hospice PUF contains information on utilization, payments, submitted charges, diagnoses, and hospice beneficiary demographics organized by provider and state. It covers calendar year 2014 and includes information on 4,025 hospice providers, over 1.3 million hospice beneficiaries, and over $15 billion in Medicare payments. With this data, it is now possible to analyze geographic variation in the delivery of hospice care, as well as variation across individual hospice providers. The Hospice PUF also includes a number of metrics on hospice beneficiary demographics and diagnoses to facilitate analyses of differences in the patient population across providers.

The third release of the Market Saturation and Utilization Data Tool includes interactive maps and supporting data sets that show national-, state-, and county-level provider services and utilization data for three reference periods and various health service areas, including hospice. The data tool can be used by CMS to monitor market saturation as a means to prevent fraud, waste, and abuse, according to the press release. The data can also be used to reveal the degree to which use of a service is related to the number of providers servicing a geographic region; provider services and utilization data by geographic regions are easily compared using an interactive map. Among the research uses for these data, CMS notes that one objective is to assist health care providers in making informed decisions about their service locations and the beneficiary populations they serve.

A JAMA “Visualizing Health Policy” infographic provides a snapshot of Medicare and end-of-life care. Produced jointly by the Journal of the American Medical Association and the Kaiser Family Foundation the infographic shows that of 2.6 million total deaths in the United States in 2014, 2.1 million were among Medicare beneficiaries. Although Medicare spent significantly more on care for people at the end of life who died in 2014 ($34,529 per person) than for other beneficiaries that year ($9,121 per person), the share of total Medicare spending for people at the end of life decreased from 18.6% to 13.5% between 2000 and 2014. Medicare spending for people at the end of life also decreased with age. Hospice use among Medicare beneficiaries at the end of life increased between 2000 and 2014 to nearly half (46%) of all beneficiaries. Medicare spending on hospice also increased during that period, from $2.3 billion to $10.4 billion. Surveys show that more than 7 in 10 people aged 65 years and older have not discussed end-of-life care with a physician and that 4 in 10 have not documented their end-of-life care wishes. Before January 1, 2016, Medicare did not reimburse physicians for patient visits to discuss end-of-life care, and as of 2016, 68% of physicians report that they have not received training for such discussions. [FN87]

In 2010, an in-depth study by Healthcare Market Resources examined the hospice industry from 2002 to 2008. The study found that from 2002 to 2007, the number of patients using hospice services grew by 100%. Medicare utilization grew 47%. However, from 2007 to 2008, use actually declined by about 1%. According to the CEO of Healthcare Market Resources, “When you have such a high number of states that have stalled or experienced a decline in growth rate, I believe we may have reached a barrier in some markets above which you can't go.” Hospices may seek to expand to gain more opportunities, or by expanding the services they offer in order to set themselves apart from the competition. [FN88]

On April 11, 2011, researchers at Dartmouth College released a report showing that the use of hospice care was increasing in New York and across the country. At the five academic medical centers in the New York City area, the average number of days patients spent in hospice care, either at home or in an institution, rose to 10.1 days in 2007 from 5.4 days in 2003. [FN89]

Parents' perspectives of health care provider actions that helped or did not around the time of an infant or child's intensive care unit (ICU) death were studied by researchers at the Florida International University College of Nursing & Health Sciences. The investigators held semi-structured interviews with 63 parents (black, white, and Hispanic) seven months following the death of the infant or child. Researchers found that what helped most was: compassionate, sensitive staff; understandable explanations of infant's/child's condition; experienced, competent nurses; providers did everything to help infant/child; and parents' involvement in care decisions. What did not help: insensitive, nonsupportive staff; conflict between providers and parents; communication problems around the death; inexperienced nurses and doctors; parents not understanding child's disease, care, complications. Conflict between providers and parents was most problematic for minority parents and mothers, the report said. [FN90]

Hospice enrollment within 30 days of death or 53?105 days of death lowers Medicare expenditures, according to a study in the March 2013 edition of Health *Affairs*. Using data from the Health and Retirement Study, 2002?08, and individual Medicare claims, and overcoming limitations of previous work, researchers found $2,561 in savings to Medicare for each patient enrolled in hospice 53?105 days before death, compared to a matched, nonhospice control. Even higher savings were seen, however, with more common, shorter enrollment periods: $2,650, $5,040, and $6,430 per patient enrolled 1?7, 8?14, and 15?30 days prior to death, respectively, the report says. Within all periods examined, hospice patients also had significantly lower rates of hospital service use and in-hospital death than matched controls. Instead of attempting to limit Medicare hospice participation, CMS should focus on ensuring the timely enrollment of qualified patients who desire the benefit. [FN91]

Although the use of hospice care for Medicare patients with advanced cancer is increasing, many patients do not receive hospice care until they are within three days of the end of their life, too short a time to take full advantage of the benefit, a study finds. The September 4 report from the Dartmouth Atlas Project also found that in 2010, despite increases in the use of hospice care, more patients were also treated in intensive care units (ICUs) in their last month of life than in the period from 2003 to 2007. The study, “Trends in Cancer Care Near the End of Life,” says the results show that much more needs to be done to address end-of-life patient preference, concluding that care for elderly patients with cancer does not necessarily reflect patient preferences, but instead is indicative of the styles of treatment in the regions or health-care systems where the patients happen to receive cancer treatment. The report also found that where patients with advanced cancer live “continues to play an important role in the care they receive.”

The report looked at the past six months of claims records for more than 200,000 Medicare patients who died in 2010. The report stated that more than 61 percent of patients in 2010 were admitted to hospice in the last month of life, while more than 10 percent were admitted within the last three days. Medicare covers hospice care for terminally ill patients with six months or less to live. “Although fewer Medicare patients with cancer died in the hospital in 2010 than in 2003?2007, aggressive treatment continues at the end of life,” the report concluded. The findings show that just as many patients were likely to receive life-sustaining treatments, such as intubation, a feeding tube, or cardiopulmonary resuscitation, in the final month of life, or to undergo chemotherapy during the last two weeks of life, in 2010 as in 2003?2007. [FN92]

A recent study published in the journal *Health Affairs* found that one reason patients don't take advantage of the comprehensive services that hospice provides is restrictive enrollment policies. The survey of nearly 600 hospices nationwide found that 78 percent had enrollment policies that might restrict patient access to care, especially for those with high-cost medical needs. The policies included prohibitions on enrolling patients who are receiving palliative radiation or blood transfusions or who are being fed intravenously. Medicare pays the majority of hospice bills, and officials have raised concerns in recent years about possible misuse of federal funds. Eighty-three percent of hospice patients are 65 or older, according to the National Hospice and Palliative Care Organization.

To qualify for hospice care under Medicare, a patient's doctor and a hospice medical director must certify that the patient has six months or less to live. Patients must also agree not to seek curative care. Once a patient chooses to enter hospice, the benefits include medical treatment for non-curative purposes such as pain and symptom management as well as emotional and spiritual support for patients and their families. However, the Health Affairs study points out that some treatments typically considered curative also may be used to manage the symptoms of a dying patient such as radiation treatments to shrink a tumor to make breathing easier. Such care can be expensive, costing upward of $10,000 a month, according to the Health Affairs study, which can put hospices in a financial bind. The Medicare program pays a fixed, per-day rate to cover all routine hospice services?last year, the base rate was $151 per day.

Large hospices that care for more than 100 patients are better positioned to absorb the cost of such treatments, experts say. However, nearly two-thirds of hospices care for 100 or fewer patients per day, according to the National Hospice and Palliative Care Organization. Worries that Medicare might deny coverage for a certain treatment that is truly palliative rather than curative may contribute to smaller hospices' more restrictive enrollment policies, the study found, says the lead author of the study, Melissa Aldridge Carlson, an assistant professor of geriatrics and palliative medicine at New York's Mount Sinai School of Medicine. “The risk is that . . . they'd have to return the money,” says the lead author of the study, Melissa Aldridge Carlson, an assistant professor of geriatrics and palliative medicine at New York's Mount Sinai School of Medicine. “So for a small hospice, it's very risky to enroll a patient who has these needs,” Carlson pointed out. [FN93]

Residents of nursing facilities that have a higher hospice penetration are less likely to be hospitalized than those in facilities with a lower hospice penetration, according to a study recently published in the Journal of the American Medical Directors Association. [FN94] Researchers found that in the last 30 days of life, 37.63% of nonhospice and 23.18% of hospice residents were hospitalized. Further, they found that every 10% increase in hospice penetration leads to a reduction in hospitalization risk of 5.1% for nonhospice residents and 4.8% for hospice-enrolled residents. The authors conclude that higher facility-level hospice penetration reduces hospitalization for both nonhospice and hospice-enrolled residents.

Care Choices Model Expands to Include Hospice

On July 20, 2015, CMS announced the hospices that have been selected to participate in the Medicare Care Choices Model. The model provides Medicare beneficiaries who qualify for coverage under the Medicare hospice benefit and dually eligible beneficiaries

who qualify for the Medicaid hospice benefit the option to elect to receive supportive care services typically provided by hospice while continuing to receive curative services.

Due to robust interest, CMS expanded the model from an originally anticipated 30 Medicare-certified hospices to over 140 Medicare-certified hospices and extended the duration of the model from 3 to 5 years. This is expected to enable as many as 150,000 eligible Medicare beneficiaries with advanced cancers, chronic obstructive pulmonary disease, congestive heart failure, and human immunodeficiency virus/acquired immunodeficiency syndrome who receive services from participating hospices to experience this new option and flexibility.

Under the model, participating hospices will provide services that are currently available under the Medicare hospice benefit for routine home care and respite levels of care, but cannot be separately billed under Medicare Parts A, B, and D. Services will be available around the clock, 365 calendar days per year, and CMS will pay a per beneficiary per month fee ranging from $200 to $400 to participating hospices when delivering these services under the model. Services will begin starting January 1, 2016 for the first phase of participating hospices and in January 2018 for the remaining participating hospices. [FN95]

Hospice Compare Website

The Centers for Medicare & Medicaid Services (CMS) unveiled the new Hospice Compare [FN96] website on August 16, 2017. The goal of Hospice Compare is to help consumers compare hospice providers on their performance and assist consumers in making decisions that are right for them. According to CMS, [FN97] providers can start a conversation with their patients and family members about how the new Hospice Compare website impacts them by:

• Explaining that the compare website provides a snapshot of the quality of care a hospice offers;

• Encouraging patients and their family members to review quality ratings; and

• Helping to strengthen patients and family members' ability to make the best decisions for their care.

The seven National Quality Forum-endorsed hospice and palliative care quality measures initially displayed on Hospice Compare are:

• Treatment preferences

• Beliefs/values addressed

• Pain screening

• Pain assessment

• Dyspnea screening

• Dyspnea treatment

• Patients treated with opioids who are given a bowel regimen

Prior to the release of data on Hospice Compare, hospices will be given the opportunity to review their quality measure results during a 30-day preview period using a Hospice Provider Preview Report, which will be issued quarterly by CMS.

Courts Rule against Medicare Hospice Reimbursement Caps

On February 28, 2011, a federal court in Oklahoma ruled against a Medicare regulation that sets reimbursement limits for hospice care providers. The U.S. District Court for the Northern District of Oklahoma declared the rule invalid that limits the amount a hospice can be reimbursed, per patient per year. The decision follows similar rulings in other states including Texas and New Mexico invalidating Medicare reimbursement caps. [FN98]

The Medicare program currently imposes a yearly aggregate payment limit on hospice providers that equals the number of beneficiaries enrolled in the benefit each fiscal year, multiplied by an amount that changes each year based on inflation, under ?1395f(i)(2)(C) of Title 42 of the US Code. Plaintiffs argue that Department of Health and Human Services' method of calculating the aggregate provider cap does not follow that method. Instead, it only counts a Medicare hospice beneficiary during a single fiscal year, even if that beneficiary has received care during other fiscal years, under 42 C.F.R. ? 418.309(b)(1), which is currently used to calculate the aggregate provider cap. [FN99]

On July 24, 2012, Tranquility Hospice Inc., an Oklahoma-based hospice, succeeded in temporarily stopping the Secretary of Health and Human Services from recouping $1.2 million in Medicare overpayments after challenging a Medicare reimbursement calculation rule in a federal district court. [FN100] The hospice was in the process of repaying HHS for $1,190,451 in hospice care overpayments when it became aware that the regulation governing Medicare's overpayment calculation, 42 C.F.R. Section 418.309(b)(1), had been invalidated by several federal appeals courts. Tranquility sued in district court, and HHS attempted to remand the case for recalculation without waiting for the court to invalidate the regulation. The court denied HHS's request, granted judgment for Tranquility, invalidated the regulation, and remanded the matter for the secretary's recalculation. At district court, Tranquility requested four items: that Section 418.309(b)(1) be declared unlawful and set aside, that HHS be enjoined from enforcing against its overpayment determinations or

hospice caps calculated by using that regulation, an order for refund, and litigation costs. The court invalidated Section 418.309(b)(1) after noting the U.S. Courts of Appeals for the Fifth, Ninth, and Tenth Circuits did the same. [FN101]

The U.S. Supreme Court on October 3, 2016, declined to weigh in on a case debating Medicare's controversial payment cap for hospice treatment. The case involves Southeast Arkansas Hospice Inc., a nonprofit hospice provider that argued that Medicare's reimbursement cap amounted to “unconstitutional taking,” a scenario in which federal regulations force private property to be used without compensation, according to *McKnight's*. [FN102] In this case, Southeast was required to deliver care to patients who had reached Medicare's hospice reimbursement cap. In March, the U.S. Court of Appeals for the Eighth Circuit ruled [FN103] that the Medicare cap didn't constitute unconstitutional taking since it “allocates the government's capacity to subsidize healthcare,” and because the provider couldn't prove that the cap stopped it from doing business. The court also noted that since Southeast voluntarily agreed to become a Medicare hospice provider, it also agreed to adhere to the program's regulations.

Rehabilitation Services at End of Life

A recent study has revealed that potentially unnecessary and harmful high intensity rehabilitation services for residents of nursing homes are increasing. The trend is on the rise for patients in the last 30 days of life, indicating that the services may be interfering with appropriate end-of-life care, according to University of Rochester Medical Center researchers. [FN104]

A desire by skilled nursing facilities to maximize reimbursement rates may be driving the trend, and has drawn the attention of federal regulators. Nursing home Medicare reimbursement rates are based on categories that place patients into resource utilization groups (RUGs) based on the complexity, intensity, and amount of staff time dedicated to their care. Patients who receive high levels of rehabilitation services fall into a category that makes these facilities eligible to collect the highest level of reimbursement for their care.

The authors of the study analyzed data from 647 nursing home facilities in New York State, focusing on residents who had received very high to ultrahigh rehabilitation services (physical, occupational, and speech therapy) during the last 30 days of life. Very high intensity rehabilitation is defined as 520 minutes or greater per week and ultrahigh as 720 minutes or greater, or the equivalent of two hours of rehab per day.

They found that residents receiving ultrahigh rehabilitation had increased by 65 percent between 2012 and 2015 and that most of the rehabilitation therapy residents received was concentrated in the last seven days of life. They also found that there was a significantly higher use of these services in for-profit nursing home compared to not-for-profit homes.

Payment for End-of-Life Planning

On October 30, 2015, CMS issued finalized 2016 Medicare rules that update payment policies, payment rates, and quality provisions for services furnished under the Medicare Physician Fee Schedule (PFS) on or after January 1, 2016. A fact sheet on the new rule is available at https://www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2015-Fact-sheets-items/2015-10-30-2.html.

The rule also finalizes a proposal that will better enable seniors and other Medicare beneficiaries to make important decisions that give them control over the type of care they receive and when they receive it.

Consistent with recommendations from the American Medical Association (AMA) and a wide array of stakeholders, CMS is establishing separate payment and a payment rate for two advance care planning services provided to Medicare beneficiaries by physicians and other practitioners. The Medicare statute currently provides coverage for advance care planning under the “Welcome to Medicare” visit available to all Medicare beneficiaries, but they may not need these services when they first enroll. Establishing separate payment for advance care planning codes to recognize additional practitioner time to conduct these conversations provides beneficiaries and practitioners greater opportunity and flexibility to utilize these planning sessions at the most appropriate time for patients and their families. CMS is also finalizing payment for advance care planning when it is included as an optional element of the “Annual Wellness Visit.”

The AMA Current Procedural Terminology (CPT) Editorial Panel and the AMA Relative Value Update Committee (RUC) recommended new CPT codes and associated payment amounts for calendar year 2015. CMS did not make the new codes payable for 2015 in order to allow the public full opportunity to comment.

For Medicare beneficiaries who choose to pursue it, advance care planning is a service that includes early conversations between patients and their practitioners, both before an illness progresses and during the course of treatment, to decide on the type of care that is right for them.

In 2016, the first year that health care providers were allowed to bill for the consultations, nearly 575,000 Medicare beneficiaries took part in conversations to discuss advance-care planning, *Kaiser Health News* reports. [FN105] Nearly 23,000 providers submitted about $93 million in charges, including more than $43 million covered by the federal program for seniors and the disabled. Use was much higher than expected, nearly double the 300,000 people the American Medical Association projected would receive the service in the first year. Still, only a fraction of eligible Medicare providers ? and patients ? have used the benefit, which pays about $86 for the first 30-minute office visit and about $75 for additional sessions.

Notices of Election

When electing hospice, a beneficiary waives Medicare coverage for any care for the terminal illness and related conditions except for services provided by the designated hospice and attending physician. A hospice, then, must file an NOE as soon as possible to record the hospice election within the claims processing system. Late filing of the NOE can result in inaccurate benefit period data, leaving Medicare vulnerable to paying non-hospice claims related to the terminal illness and related conditions, and beneficiaries potentially liable for sharing associated costs. A final rule in 2014 finalized a requirement that the NOE be filed within five calendar days after the effective date of hospice election. When the NOE is filed more than five calendar days after the effective date of election, the hospice would be financially liable for the cost of the beneficiary's care on days between the effective date of hospice election and the date of NOE filing, according to the fact sheet. [FN106]

Beginning in 2018, hospice notices of election can be submitted electronically, via Electronic Data Interchange, according to CMS. In its memo detailing the changes to the CMS Manual System, [FN107] CMS explained that the hospice industry had requested the change.

Currently, to be covered by the Medicare hospice benefit, a beneficiary must sign an election statement, indicating their choice of hospice care instead of curative treatment. The hospice notifies the Medicare program that a beneficiary's election is on file by submitting a Notice of Election (NOE). The NOE is a submitted like a claim. The hospice key-enters the NOE information into the Medicare contractor's Direct Data Entry (DDE) screens. The NOE processes through Medicare claims systems, which updates beneficiary records and later uses the information to adjudicate hospice claims. Currently, hospices may only submit NOEs using DDE or paper claim submissions.

Under the manual change, Medicare will implement submission of NOEs via electronic data interchange (EDI). Receipt of NOEs via EDI support Medicare business needs, since prompt and error-free NOEs are increasingly important to a variety of payment policies, the industry maintains. EDI transmission of NOEs would reduce, and potentially eliminate, problems with NOEs that result from errors during the Direct Data Entry process. Hospices could export data from their electronic medical record or other software system into the EDI format without human intervention. The change takes effect on January 1, 2018.

Dialysis Patients

A recent study suggests that very few Medicare patients on dialysis receive hospice care at the end of life, and when they do, they're often enrolled too briefly to fully benefit from these services. Medicare, which covers Americans with kidney failure, will not pay for dialysis and hospice at the same time. This forces terminally ill patients to choose between continuing on dialysis or accessing hospice care, which may provide more comfort and support at the end of life, researchers note in JAMA Internal Medicine. [FN108]

Researchers in the current study examined data on more than 770,000 dialysis patients covered by Medicare who died between 2000 and 2014. Just one in five were receiving hospice services when they died.

Among patients who did receive hospice care, 42 percent were enrolled for three or fewer days. Compared with dialysis patients who didn't receive hospice care, those enrolled in hospice for three or fewer days were more likely to have been hospitalized or admitted to intensive care units in the last month of life. But they were less likely to die in the hospital or undergo invasive procedures.

Lead study author Dr. Melissa Wachterman points out that terminal kidney failure patients can have intense pain and worse quality of life than people with cancer or dementia at the end of life. “Patients with kidney failure stand to benefit greatly from the care hospice has to offer and yet they are about half as likely to receive hospice as those with other serious illnesses like cancer and heart disease,” Wachterman said.

B. Concerns over Use of General Patient Hospice Care

Lengthy stays by hospice patients receiving general inpatient care (GIP), as well as the use of GIP in inpatient hospice units, raise questions about whether hospices are providing the care correctly, a report from the HHS Office of Inspector General stated. Released on May 3, the report, *Medicare Hospice: Use of General Inpatient Care* (OEI-02-10-00490) said the provision of hospice GIP needs “further review to ensure that hospices are using GIP as intended and providing the appropriate level of care.” According to the report, hospice GIP is intended for short-term pain control or symptom management provided in an inpatient facility that cannot be managed in other settings. It is the second most expensive level of hospice care and may be provided in one of three settings: a hospice inpatient unit, a hospital, or a skilled nursing facility. CMS staff have expressed concerns about possible misuse of GIP, such as care being billed for but not provided, long lengths of stay, and beneficiaries receiving care unnecessarily. The OIG based the study on Medicare Part A hospice claims submitted during 2011. The OIG report found that 33 percent of hospice beneficiaries receiving GIP in 2011 had inpatient stays of more than five days, and 11 percent had stays of more than 10 days. The report also found that the majority (58 percent) of GIP stays in 2011 were at hospices with inpatient units. Medicare paid $1.1 billion in payments for GIP in 2011, which accounted for 8 percent of all Medicare payments for hospice care. [FN109]

C. End-of-Life Costs on the Rise

With respect to cost of care at life's end, the *Dartmouth Atlas of Health Care 2008* documented figures from more than 90 academic medical centers and showed it can vary widely. [FN110] According to research focused on the nation's top-ranked hospitals, U.C.L.A. Medical Center averaged Medicare spending in the last two years of life at $93,842 per patient. At the low end with $53,432 per beneficiary was the Mayo Clinic's main teaching hospital in Rochester, Minnesota. Other well-known institutions, including Baltimore's

Johns Hopkins, Boston's Massachusetts General, and Ohio's Cleveland Clinic, showed figures in the middle range. The study also noted that hospitals providing more care or more intensive care did not always mean that better results were achieved for their patients. In noticing the cost disparities, federal officials are now looking at improving efficiencies of facilities in high-cost regions, which could result in billions of dollars in savings for Medicare.

Recent studies have found that the costs of end-of-life care continue to increase and show no signs of leveling off, according to research from the United States and Canada published in the Archives of Internal Medicine. But other trends over the past decade, including a sharp increase in use of hospice services, could point the way toward bringing these costs down while improving patient care, said Dr. Jonathan Bergman of the University of California in Los Angeles, author of one of the studies. Patients receiving hospice care typically forgo life-saving or potentially curative treatments and instead receive treatment of their symptoms. Bergman and his colleagues found that though hospice enrollment among dying prostate cancer patients jumped from around 30 percent in 1992 to more than 60 percent in 2005, the timing of when they entered hospice didn't change. One-quarter of patients were in hospice for seven days or less, which is “too brief to maximize the benefit of enrollment,” the researchers write. Another study, this one of dying heart-failure patients, found that under the current U.S. system, more hospices didn't necessarily mean less spending. A study of nearly 230,000 Medicare patients who died of heart failure between 2000 and 2007 found that use of hospice “dramatically” increased, from 19 percent in 2000 to nearly 40 percent in 2007. But rates of hospitalization in the last six months of life held steady at around 80 percent. Also, more people who were hospitalized spent time in an intensive care unit (ICU), and average time in the ICU also increased. Costs rose from about $28,000 per patient for their last six months of life in 2000 to $36,000 in 2007. “We might be able to do a better job with end-of-life care and cut costs not by rationing care but by making it more rational and treating each patient based on their original goals,” Bergman said. [FN111]

A study conducted by the Mount Sinai School of Medicine has found that for nearly a quarter of Medicare beneficiaries, out-of-pocket health care costs exceed their total assets (not including primary residences), in the last years of their lives. Researchers found that those who had to pay for the cost of dementia care were particularly hard hit. The study, funded by the National Institute on Aging, analyzed data over six years from 3,209 Medicare beneficiaries. Those with dementia or Alzheimer's disease averaged $66,155, versus those patients with gastrointestinal disease or cancer, who spent an average of $31,069. “Medicare provides a significant amount of healthcare coverage to people over 65, but it does not cover co-payments, deductibles, homecare services, or non-rehabilitative nursing home care,” noted the study's lead author, Amy S. Kelley, M.D., a Mount Sinai School of Medicine professor. The study was published online in the Journal of General Internal Medicine. [FN112]

Kaiser Health News reports that nearly one in three Medicare patients undergo an operation in the final year of life, even though evidence shows that many are more likely to be harmed than to benefit from it. [FN113] A 2011 study, reported in *The Lancet,* researched the deaths in 2008 of fee-for-service Medicare beneficiaries in their last year of life. It found that 31.9% of the beneficiaries had surgical procedures during the year before death and 18% underwent a procedure in their last month of life. The researchers examined the relation between receipt of an inpatient procedure and both age and geographical region.

Dr. Rita Redberg, cardiologist at the University of California-San Francisco, believes that the

practice is driven by financial incentives that reward doctors for doing procedures, as well as a medical culture in which patients and doctors are reluctant to talk about how surgical interventions should be prescribed more judiciously.

Although about 25 percent of Medicare spending in the U.S. occurs in the last year of people's lives, a new study finds that there is very little spending on patients whose death within the year is highly likely. For example, the researchers discovered that less than 5 percent of Medicare spending is applied to the single highest-risk percentile of all individuals?and their predicted one-year mortality rate is just 46 percent. “What we discovered is, very little money is spent on people who we know with high probability are going to die in a short amount of time,” Co-author Amy Finkelstein says. In fact, fewer than 10 percent of people who die in a given year have a predicted one-year mortality rate over 50 percent. The researchers found that even when people are admitted to a hospital in what turns out to be their last year of life, fewer than 4 per cent of those patients have a predicted one-year mortality rate of 80 percent or higher at the time of admission.

D. Inquiries into Nursing Home Hospice Services Funding

Prompted by claims by the American Health Care Association of the long-term care industry's status as an economic and job-creating powerhouse, critics are pressing for further inquiries into how nursing homes are financed and operated, especially those facilities that provide hospice services. Data released in January, 2011 by the health care group show that in 20 states, long-term care is one of the top 10 employers and provides over 100,000 jobs in eight states. Critics say the system needs to be reformed so that hospice patients can receive care in their own homes. They also note that while flat-rate Medicare might pay a nursing home $110 to $130 per day, the rate soars by an additional $130 per day if a resident becomes a hospice patient at the same site. [FN114]

According to Medicare data, Medicare spending for the benefit had more than tripled from $2.9 billion in 2000 to just over $10 billion in 2007. The Medicare Payment Advisory Commission has recommended to Congress that the HHS Inspector General investigate the financial relationships between hospices and long-term care facilities, and to determine whether there may be a “conflict of interest.” The commission also wants the IG to look at differences in patterns of nursing home referrals and the enrollment process and to look

for spikes in enrollment. MedPAC also asked the IG to examine hospice marketing materials and admissions practices to determine if there are potential correlations between length of stay and deficiencies in marketing or admissions practices. [FN115]

The Inspector General found that Medicare spending on nursing home hospice patients increased by 69% over four years. [FN116] Now, regulators are recommending a reduction in payment levels for nursing home-based hospice patients. Medicare spending on hospice patients in nursing facilities jumped from $2.6 billion in 2005 to $4.3 billion in 2009, according to the audit. It found about 58% of increased Medicare outlays were the result of higher enrollment and the length of stays. Hospices with more than two-thirds of their patients in nursing homes earned on average $21,306 per patient, which was $3,182 more than the overall average cost per hospice patient, the audit also found. The report recommends that CMS "monitor hospices that depend heavily on nursing facility residents" and "modify the payment system for hospice care in nursing facilities." CMS said in a written response that it would move to reduce payment levels for nursing home-based hospice, per the IG report. [FN117]

Reporting requirements for hospice providers operating in skilled nursing facilities have been clarified. On January 31, 2014, CMS released revisions to the Medicare Claims Processing manual intended to clarify requirements for hospice providers operating in skilled nursing facilities. The Affordable Care Act authorized CMS to collect additional data on hospice claims. The latest manual update, scheduled to take effect for all claims with dates of service on or after April 1, 2014, mandates additional data reporting. The additional data reporting includes visit reporting for general inpatient care, reporting the facility National Provider Identifier (NPI) where the care was provided when not provided at the billing hospice facility, and reporting of infusion pumps and prescription drugs. [FN118]

According to a report by the HHS Inspector General, about $33.6 million in Medicare Part D drug funds was spent on prescription drugs in 2009 that likely should have been covered under the hospice benefit. "As a result, the Medicare program could be paying twice for prescription drugs for hospice beneficiaries: once under the Medicare Part A hospice per diem payments and again under Medicare Part D," the report says. [FN119] Under Part D, CMS makes estimated monthly subsidy payments to prescription drug plan (PDP) sponsors for each enrollee. The PDPs pay the pharmacies when the drugs are dispensed. Under the hospice benefit, prescription drugs related to beneficiaries' terminal illnesses, used primarily for symptom control, are covered by CMS under per diem payments to hospice organizations. "[T]herefore, Medicare Part D should not pay for them," the report said. Although CMS sends monthly information to PDPs indicating whether a beneficiary has elected hospice care, the report said that the Part D sponsors contacted for the research did not have procedures to identify the drugs that should have been covered under hospice payments. The report says that in 2009, 198,543 hospice beneficiaries received 677,022 prescription drugs through Part D that potentially should have been covered under payments made to hospice organizations. The OIG recommends that CMS: educate sponsors, hospices, and pharmacies that it is inappropriate for Medicare Part D to pay for drugs related to hospice beneficiaries' terminal illnesses; perform oversight to ensure that Part D is not paying for drugs that Medicare has already covered under the per diem payments made to hospice organizations; and require sponsors to develop controls that prevent Medicare Part D from paying for drugs that are already covered under the per diem payments. [FN120]

F. Effect of Advance Directives

Researchers from the University of Michigan have found that individuals who have advance directives are more likely to receive palliative care and are less likely to die in a hospital. Medicare expenditures for enrollees with advance directives also are lower, especially in higher-spending regions of the United States, the study noted. The study is one of the first to look at national data linking end-of-life spending, treatments and advance directives. Researchers analyzed records of health and retirement study participants who died between 1998 and 2007, including their Medicare claims, and interviews were conducted with beneficiaries' next of kin. The study was published in the October 5 issue of the Journal of the American Medical Association. [FN121]

Oregon Health & Science University (OHSU), in partnership with Silicon Valley startup Vynca, Oregon POLST, and the Oregon POLST Registry, on June 15, 2015, announced the launch of ePOLST, a fully integrated electronic version of the Physician Orders for Life-Sustaining Treatment, commonly known as POLST, which will assist health care systems in more accurately recording and accessing the wishes of patients who are nearing the end of life.

The POLST form was created in 1990 in an effort to ensure the wishes of those with advanced illness or frailty are followed. POLST programs have been adopted or are in development in 43 states across the country. POLST forms are strongly associated with desired care received. A survey of patients showed that less than 10 percent of patients want to die in the hospital. Unfortunately, without a POLST form, four times that many still do.

In the first phase of the launch, ePOLST allows OHSU clinicians to electronically and more quickly and accurately submit a POLST form, drastically reducing the need for paper forms, which are error-prone. OHSU clinicians can also now easily view a patient's POLST form, which is located at the top of their EPIC electronic health record, if they have one. This is critical in crisis situations where care teams are making decisions about treatment options. In the next phase, OHSU clinicians will be able to electronically search the Oregon POLST Registry through ePOLST, which will make it easier to find POLST forms from other health care systems.

New educational materials have been developed to help patients more fully understand how POLST orders can turn their wishes to have or to limit treatment in to action as medical orders. To assure the quality of these important conversations we are teaching

clinicians and care teams how to use the newly available “just in time” patient educational materials now linked to the ePOLST Program.

G. Quality of Hospice Care

A final rule extending hospice quality reporting requirements to subsequent years was published by CMS on November 8, 2012. [FN122] As authorized by the Affordable Care Act, beginning with FY 2014 and each subsequent fiscal year, the Secretary of HHS shall reduce the market basket update by 2 percentage points for any hospice that does not comply with the quality data submission requirements. Depending on the amount of the annual update for a particular year, a reduction of 2 percentage points could result in the annual market basket update being less than 0.0 percent for a FY and may result in payment rates that are less than payment rates for the preceding FY. To meet the hospice quality reporting requirements affecting the FY 2014 payment determination, hospices are submitting two measures: the Structural/QAPI measure and the NQF #0209 measure. The data collection period is October 1 to December 31, 2012. Data submission can begin on January 1, 2013. The structural measure must be submitted by January 31, 2013 and the NQF #0209 by April 1, 2013.

In a review of 120 Medicaid hospice claims paid to **Illinois** hospices in 2009 and 2010, the HHS Office of Inspector General found that CMS's reliance on Illinois licensure requirements “could not ensure quality of care and that adequate protection was provided to Medicaid hospice beneficiaries,” according to the OIG report. [FN123] The OIG determined in most cases that hospices did not meet State hospice licensure requirements related to hospice workers. Of the 120 claims that we sampled, 110 involved direct care provided by unqualified hospice workers and that on the basis of the sample results, an estimated 51,374 of the 56,044 claims covered by the review were associated with unqualified hospice workers. For example, of the 120 claims reviewed, 110 involved workers that lacked the initial health evaluation requirements, 20 without background checks, and 17 that didn't meet the training requirements.

Medicare patients in hospice care were less likely to be visited by professional staff in the last two days of life if they were black, dying on a Sunday, and receiving care in a nursing home setting, a new study has found. The study, published in *JAMA Internal Medicine*, [FN124] examined the frequency of visits by professional staff provided to 661,557 Medicare hospice beneficiaries who died between October 1, 2013 and September 30, 2014. Medicare regulations require that hospice care centers report daily the frequency and duration of patient visits by professional staff, as well as the type of hospice staff who conduct those visits. The study found:

• 12.3% of the patients received no professional staff visits in the last 2 days of life.

• black patients were less likely to have any visits than were white patients (15.2% vs 12.0%)

• those dying in a nursing home were 1.74 times less likely to have any visits than those dying at home

• those dying on a Sunday were 3.35 times less likely to have a visit compared with persons dying on a Tuesday, and

• the number of patients receiving no visits in the last 2 days varied by state, ranging from 3.8% in Wisconsin to 19.7% in Alaska.

The authors noted that their study did not take into account the severity of the symptoms of the hospice patients, or family preferences for visits. The results still pinpoint disparities in hospice care, researchers said, which is especially relevant as the Centers for Medicare & Medicare Services evaluates reforms.

H. Lengthier Hospice Stays and Rising Profits

The Washington Post reports that over the past decade, the number of “hospice survivors” in the U.S. has risen dramatically, in part because hospice businesses earn more by recruiting patients who aren't actually dying. Hospice patients are expected to die; to enroll a patient, two doctors certify a life expectancy of six months or less. But healthier patients are more profitable because they require fewer visits and stay enrolled longer, the *Post*'s investigation found. Between 2002 and 2012, the proportion of patients who were discharged alive from hospice care rose about 50 percent according to the *Post* analysis of more than 1 million hospice patients' records over 11 years in California. The average length of a stay in hospice care also jumped substantially over that time, in California and nationally, according to the analysis, and profit per patient quintupled, to $1,975, California records show, according to the analysis.

Hospice care has evolved into a $17 billion industry dominated by for-profit companies, and roughly $15 billion of industry revenue came from Medicare last year. The *Post* cites AseraCare, one of the nation's largest for-profit chains, as an example: about 78 percent of patients who enrolled at the Mobile, Ala., branch left the hospice's care alive, and as many as 59 percent of patients left the AseraCare branch in nearby Foley, Ala., alive, according to company records.

There is financial incentive for hospice firms to enroll healthier patients. Medicare pays a hospice about $150 a day per patient for routine care, regardless of whether the company sends a nurse or any other worker out on that day. That means healthier patients, who generally need less help and live longer, yield more profits, which may be costing Medicare billions of dollars a year, the *Post* reports. In fact, MedPAC, the Medicare watchdog group created by Congress, has reported that in 2011, nearly 60 percent of Medicare's hospice expenditure of $13.8 billion went toward patients who stay on hospice care longer than six months. Furthermore, data suggests that the trend toward longer stays is a response to the financial incentive: while the average nonprofit serves a patient for 69 days, the average for-profit hospice serves a patient for an average of 102 days, according to MedPAC.

MedPAC has been recommending that the payments to hospice companies be revised to eliminate the financial incentive for improper care, but Medicare has not yet done so. The hospice industry is opposed to fundamental changes to the payment system; an official

with a hospice industry group says that the current payment system is sound and that tampering with it could have unintended consequences, noting that two doctors certify a life expectancy of six months or less for hospice patients, the *Post* reports. [FN125]

OIG Finds Medicare Hospices Have Financial Incentives to Provider Care in Assisted Living Facilities

In a report released January 13, 2015, the OIG recommends that CMS reform the hospice payment system, collect data, and develop quality measures for hospices. [FN126] Although focused on assisted living facilities (ALFs), the OIG notes its recommendations pertain to the hospice benefit more broadly. The OIG report analyzed all Medicare hospice claims from 2007 through 2012, using Certification and Survey Provider Enhanced Reports data and Healthcare Cost Report Information System reports for supplementary information on hospice characteristics.

The OIG found Medicare payments for hospice care in ALFs more than doubled in 5 years, totaling $2.1 billion in 2012. Hospices provided care much longer and received much higher Medicare payments for beneficiaries in ALFs than for beneficiaries in other settings. Hospice beneficiaries in ALFs often had diagnoses that usually require less complex care. Hospices typically provided fewer than 5 hours of visits and were paid about $1,100 per week for each beneficiary receiving routine home care in ALFs. Also, for-profit hospices received much higher Medicare payments per beneficiary than nonprofit hospices. The report raises concerns about the financial incentives created by the current payment system and the potential for hospices to target beneficiaries in ALFs because they may offer the hospices the greatest financial gain. Together, the findings in this and previous OIG reports show that payment reform and more accountability are needed to reduce incentives for hospices to focus solely on certain types of diagnoses or settings.

The OIG recommends that CMS, as part of its ongoing hospice reform efforts: (1) reform payments to reduce the incentive for hospices to target beneficiaries with certain diagnoses and those likely to have long stays, (2) target certain hospices for review, (3) develop and adopt claims-based measures of quality, (4) make hospice data publicly available for beneficiaries, and (5) provide additional information to hospices to educate them about how they compare to their peers. CMS agreed with all five recommendations.

I. Hospice Benefits in Medicare Advantage Plans

The Congressional advisory group Medicare Payment Advisory Commission (MedPAC) voted on a draft recommendation on January 16, 2014, to include hospice benefits in Medicare Advantage (MA) coverage. Currently, when MA enrollees start hospice care, MA plans and fee-for-service Medicare split the cost of their care: traditional Medicare pays hospice providers for services related to terminal conditions, and MA plans continue to pay for other services unrelated to hospice. Hospice facilities coordinate care for services they provide, but not the rest of care that patients need. Commissioners say this policy runs counter to the all-inclusive care coordination for which MA plans otherwise are responsible. MedPAC staff feels that MA plans would be in a better position to coordinate care and plans could offer concurrent care as a supplemental benefit, if hospice were included in MA coverage. Medicare would have to pay higher capitation rates to account for the additional benefits and risk scores would need to be recalculated. MedPAC Executive Director Mark Miller told commissioners that MA plans with which commission researchers spoke are generally agreeable to including hospice, and indeed most organizations with MA plans already offer hospice benefits in other policies. Some but hospice providers, however, worry about being left out of MA networks. [FN127]

For FY 2017, hospice providers will receive a 2.1% boost in Medicare payments, under a final rule published on August 5. [FN128] The increase is slightly less than the original 2.8% increase that was included in the proposed rule released in April 2016. Based on a 2.7% inpatient hospital market basket update, the increase will bring an additional $350 million in funding to hospice providers. Included in the final rule:

· Hospice cap will be adjusted from $27,821 to $28,405

· Hospice Visits When Death is Imminent quality measure (assesses staff visits in patient's last days of life)

· Hospice and Palliative Care Composite Process Measure (assesses percentage of patients who received care consistent with the guidelines.

J. Effect of Hospice Care on Medicare Hospitalizations and Costs

Medicare patients with poor-prognosis cancers who received hospice care had significantly lower rates of hospitalization, ICU admissions, and invasive procedures than those without at the end of life, a study published in *JAMA* finds. [FN129] During the last year of life, significantly lower health care expenditures were reported as well.

The article states that uncertainties regarding how hospice affects health care utilization and costs have hampered efforts to promote it. While more patients with cancer use hospice now than ever before, there are indications that the intensity of care outside of hospice is increasing, and the length of hospice stay decreasing.

This study, led by Ziad Obermeyer of Brigham and Women's Hospital and Harvard Medical School, used data from Medicare beneficiaries with poor-prognosis cancers (including, brain, pancreatic, and metastatic malignancies) and matched those enrolled in hospice before death to those who died without hospice care. A nationally representative 20% sample of Medicare fee-for-service beneficiaries who died in 2011 was studied. Matching patients based on various criteria produced a hospice and nonhospice group, with 18,165 in each. The median duration of hospice care was 11 days.

Significantly greater health care utilization was found in the nonhospice group, largely for acute conditions not directly related to cancer and higher overall costs. Rates of hospitalizations (65% vs 42%), ICU admissions (36% vs 15%), invasive procedures (51% vs 27%), and death in a hospital or nursing facility (74% vs 14%) were higher for nonhospice beneficiaries compared to hospice patients. In addition, costs during the last year of life were $62,819 for hospice beneficiaries and $71,517 for nonhospice beneficiaries. [FN130]

O. Medicaid Funding

For those individuals who are dually eligible for Medicare and Medicaid who elect the Medicare hospice benefit, Medicare is financially responsible for the hospice care and the Medicaid program is the third-party payor responsible for the nursing facility room and board expense. For the nursing facility room and board care, the Medicaid program must provide for payment in an amount equal to at least 95% of the Medicaid daily nursing facility rate (the rate the state Medicaid program pays for nursing facility services furnished to an individual who has not elected to receive hospice care). Historically, the Medicaid program has paid the hospice provider for the nursing facility room and board expenses of dually eligible individuals who elect the hospice benefit, and the hospice provider has then passed through this payment to the nursing facility.

As reported by *The Philadelphia Inquirer*, *Kaiser Health News* has suggested that a new approach may combine palliative and hospice care to allow active treatment and end-of-life care to occur simultaneously for the terminally ill. [FN131] As opposed to standard Medicaid/ Medicare protocols stipulating that one “must give up aggressive treatment to get end-of-life counseling and care,” the new initiative, says *KHN*, “may be especially useful for people using dialysis to extend their lives, and those waiting for organ transplants that may not come in time.” In addition, “the change may encourage people with any kind of terminal illness to take advantage of hospice care earlier.” As documented by *KHN*:

The new law instructs Medicaid, the state-federal program for the poor, to cover simultaneous hospice and curative care for children with terminal illnesses immediately. And it directs the federal Medicare program, which covers seniors and disabled people, to launch up to 15 pilot projects around the country to test the concept. If the experiment is deemed successful and doesn't increase costs, then Medicare could make the benefit available to everyone in hospice.

P. Accrediting of Hospices under CMS Final Notice

In a final notice issued March 27, 2009 [FN132] CMS announced the approval of a deeming application from The Joint Commission for continued recognition as a national accreditation program for hospices requesting participation in Medicare or Medicaid. Effective dates for the notice are June 18, 2009 through June 18, 2015. A press release from The Joint Commission stated, “The six-year designation means that hospice organizations accredited by The Joint Commission will be “deemed' as meeting Medicare and Medicaid certification requirements and are eligible for Medicare reimbursement — The Joint Commission's standards for hospice meet or exceed those established for the — programs.” [FN133] An independent, not-for-profit entity, The Joint Commission provides accreditation and certification for approximately 15,000 U.S. health care organizations and programs.

On November 5, 2013, CMS released a final notice announcing a decision to approve the Accreditation Commission for Health Care for continued recognition as a national accrediting organization for hospices that seek to participate in Medicare or Medicaid. This final notice becomes effective November 27, 2013 through November 27, 2019, and appears in the November 5, 2013 Federal Register. [FN134]

Q. Costs of Younger vs. Older Seniors

Contrary to widely held beliefs about the costs of end-of-life care, younger seniors, with potentially longer life expectancies, are amassing the largest medical bills, and not Americans in their 80s and 90s, according to a new analysis that examines the relative costs of end-of-life care.

The study, conducted by the Kaiser Family Foundation, analyzed Medicare claims data for 2014 for all beneficiaries who died the same year. It found that that average Medicare spending per person peaked at age 73?at $43,353. That compared with $33,381 per person for 85-year-olds, and $27,779 per person among 90-year-olds.

Kaiser researchers said their findings suggest that providers, patients, and their families may favor more costly, lifesaving care for younger seniors, and turn to hospice care when patients are older. Medicare covered eight of 10 people in the U.S. who died in 2014, establishing it as the largest insurer of medical care provided at the end of life, according to the Kaiser report.

Medicare spent an average of $34,529 on each of them, and most of that money (51%) went to inpatient hospital expense. The rest was spent mostly on skilled nursing facilities, home health care and hospice (23%) or physicians (13%) or medication, 6%. Overall, the largest portion, 31%, of per capita spending for all beneficiaries goes to inpatient hospital expenses.

Overall, the aging baby boomer population is leading to a decrease in the growth of spending on patients' last years of life. More beneficiaries are younger and healthier, and they are living longer, so their last years of life are cheaper.

Kaiser's analysis covered only traditional Medicare beneficiaries during the calendar year in which they died and did not include spending in the full 12 months before their deaths. The report also did not include spending on beneficiaries in Medicare Advantage because data was unavailable. [FN135]

R. Legislative Activity

Federal

Respite Care: Bills that would allow hospice patients to receive respite care in their homes, as opposed to an inpatient facility, nursing home, or hospital during the COVID-19 pandemic have been introduced in the House and Senate. On August 4, 2020, Senators Sherrod Brown (D-Ohio) and Shelley Moore Capito (R-W.Va.) introduced The COVID-19 Hospice Respite Care Relief Act of 2020 (2019 CONG US S 4423). In the House, Reps. Troy Balderson (R-Ohio) and Donna Shalala (D-Fla.) introduced substantially similar legislation. Respite is one of four levels of hospice care that Medicare covers, intended to provide a break for family caregivers. The other three levels of care are routine home care, continuous home care, and general inpatient care. Medicare typically covers as many as five days of respite care, typically on an inpatient basis. This legislation would extend that period to 15 days as well as allow providers to offer those services in the patient's home during times of federally declared national emergencies, such as the COVID-19 pandemic.

Telehealth: 2019 CONG US HR 8156, introduced September 1, 2020, would extend use of telehealth to conduct a face-to-face encounter prior to recertification of eligibility for hospice care, for a limited period, during the COVID emergency.

California

2019 CA A.B. 856 (NS), introduced February 20, 2019, would allow a credit against personal income taxes for each taxable year beginning on or after January 1, 2020, and before January 1, 2024, in an amount equal to 25% of the amount paid or incurred during the taxable year, not compensated for by insurance or otherwise, by a qualified taxpayer, as defined, for home care services (including hospice), not to exceed $5,000.

Delaware

2019 DE S.B. 219 (NS), introduced June 10, 2020, relating to viatical settlements.

Illinois

2019 IL H.B. 3037 (NS), introduced February 15, 2019, would require the Department of Healthcare and Family Services to make all room and board medical assistance payments directly to long-term care providers and all hospice care payments directly to hospice care providers whenever recipients of medical assistance opt to receive hospice care at long-term care facilities.

Iowa

• 2019 IA H.F. 295 (NS), introduced February 6, 2019, relating to reimbursement for dually eligible Medicare and Medicaid beneficiaries receiving the Medicare hospice benefit in a nursing facility.

• 2019 IA S.F. 542 (NS), introduced March 7, 2019, relating to reimbursement for dually eligible Medicare and Medicaid members receiving the Medicare hospice benefit and Medicaid-only members electing the hospice benefit in a nursing facility.

Minnesota

2019 MN S.F. 498 (NS), introduced January 28, 2019, would expand the senior citizens property tax deferral program to terminally ill homeowners.

New York

• 2019 NY A.B. 2889 (NS), introduced January 28, 2019, would made hospice providers eligible for access funding under the health care facility transformation program.

• 2019 NY S.B. 1814 (NS), introduced January 16, 2019, would establish reimbursement mechanisms for access to hospice services for residents of assisted living programs.

Vermont

2019 VT H.B. 611 (NS), adopted October 5, 2020, establishing an Older Vermonters Act that provides a system of services, supports, and protections for Vermont residents 60 years of age or older, including hospice services; establishing annual inflationary increases to Medicaid reimbursement rates for home- and community-based service providers.

V. ADVANCE CARE DIRECTIVES

Most hospitals, nursing homes, home health agencies, and HMOs routinely provide information on advance directives at the time of admission. They are required to do so under a federal law called the Patient Self-Directed Determination Act of 1990 (PDSA).

The PSDA simply requires that most health care institutions (but not individual doctors) do the following:

• Give patients at the time of admission a written summary of your health care decision-making rights. Each state has developed such a summary for hospitals, nursing homes, and home health agencies to use.

• Provide the facility's policies with respect to recognizing advance directives.

• Ask patients if they have an advance directive, and document that fact in their medical records. It is up to the individual patient to make sure providers get a copy of it.

• Educate their staff and community about advance directives.

• Never discriminate against patients based on whether or not they have an advance directive. Thus, it is against the law for them to require either that you have or not have an advance directive. [FN136]

A. Definitions and Issues

The terms “advance directive” and “advance care directive” refer to two types of legal documents that enable individuals to plan and communicate their end-of-life wishes in the event that the individuals are unable to communicate their wishes themselves. These are a health care proxy (also known as a medical power of attorney or durable power of attorney for health care) and a living will.

A health care proxy allows an individual to appoint another person as the individual's health care agent, thus authorizing the agent to make medical decisions on the individual's behalf in the event that the individual is incapacitated and unable to make his or her own medical decisions. A health care proxy is typically a family member who accepts legal responsibility or medical power of attorney to make decisions on behalf of the incapacitated patient. Healthcare proxies are designated through a legal document, signed, and authorized by a patient prior to becoming incapacitated.

A living will allows an individual to document his or her wishes concerning medical treatment at the end of life. A living will is also a legal document, but rather than assigning an individual to make decisions on behalf of a patient, a living will enumerates a patient's health wishes in writing. Such specifications may include the types of treatment a patient might wish to receive, as well as the duration of treatment.

A living will may also contain “do not resuscitate” (DNR) orders, which detail the circumstances under which a patient would not want medical professionals to go to great lengths to try to save the patient's life. People who do not have living wills with DNR clauses may opt to sign a DNR form with physician oversight while being treated at a health facility. A designated health care proxy also may instruct medical staff not to revive a patient, but such instructions do not require a written designation from the patient.

The highly publicized story of Terri Schiavo in 2005 resulted in heightened public awareness of the importance of advance care directives. In 1990, Ms. Schiavo suffered a neurological injury and fell into a vegetative state. Ms. Schiavo, who was only 26 at the time, had not designated a health care proxy, nor had she authored a living will. Following her brain injury, she was able to breathe without respiratory assistance, but was unable to eat or drink on her own and received nourishment through a feeding tube. After more than a decade without noticeable improvement, Ms. Schiavo's husband wanted to remove the feeding device and allow her to pass away, but her parents wanted her to be kept alive by any possible means. Because Ms. Schiavo had not specified any advance care directives, the decision to remove her feeding tube led to a court battle between her husband and her parents. The Florida Legislature granted then Gov. Jeb Bush (R) the power to require that Ms. Schiavo continue to receive nourishment. At the start of 2005, Terri Schiavo's husband was granted a court order to remove her feeding tube, but her parents sought and won a temporary stay. The U.S. Congress passed a bill in mid-March 2005 that sent this and any similar future cases to federal court. [FN137] Ultimately, the U.S. Supreme Court ruled that Mr. Schiavo could authorize the removal of Ms. Schiavo's feeding tube. [FN138] Ms. Schiavo died March 31, 2005. Had Ms. Schiavo signed advance care directives prior to her injury, the ensuing family, moral, and legal battles might not have been necessary.

An AARP Bulletin Poll, conducted in 2007, entitled “Getting Ready to Go,” investigated related to end-of-life decisions and advance care directives. [FN139] Among the findings:

• Most people have some knowledge of the steps involved with completing advance directives, but few have taken action.

• Older individuals are more prone to take action than those who are younger.

• Healthy individuals' actions differ from those who are less healthy.

• As individuals age, differences in actions with regard to health status disappear.

• Parents take action more often than their children do.

All 50 states recognize advance care directives. However, the laws governing advance care directives and the forms for creating them vary from state to state. Laws governing the procedures and approved forms for advance care directives are continually in flux.

In a published report released in 2016, researchers found that making sure residents' care preferences are consistently recorded and updated in medical records is crucial to providing quality end-of-life care. The report states that advanced care planning is an important step for patients and families to take, especially at a time when nearly a quarter of hospitalized older adults are not able to make their own end-of-life decisions. The study was conducted by a team of researchers from the Regenstrief Institute, Indiana University Center for Aging Research and the Indiana University School of Nursing, and published online in the Journal of Pain and Symptom Management.

Inconsistencies in the way care preferences are documented and carried out by nursing homes and hospitals may mean a patient's preferences are not honored. The team's report, set out to measure care consistency with documented care practices, and how healthcare providers can improve that consistency.

The team of researchers recommends five best practices for providers to ensure consistency with their residents care preferences:

• Documenting each resident's specific treatment preferences, such as “do not place feeding tube” instead of “comfort care,” in the medical record

• Making sure treatment preferences are recorded in a consistent format and location in each medical record

• Reviewing and updating preferences regularly as residents' clinical conditions change

• Creating data collection strategies to document decisions to withhold medical interventions

• Implementing a consistent measurement approach, such as a required percentage for agreement with care preferences, that can be used to compare with other providers. [FN140]

Researchers at the University of California at San Francisco find that current legal restrictions significantly compromise the clinical effectiveness of advance directives. The study, which surveys medical and legal literature from across the United States, appears in the January 18, 2010 issue of the *Annals of Internal Medicine*. Advance directives allow patients to designate health care decision-makers and specify health care preferences for future medical needs. The authors recommend that advance directive law and advance care planning evolve into a more flexible, relationship-and communication-based model, in which any type of advance care planning tool or discussion can help guide clinical care.

Authors of the study list a number of legal barriers to the clinical effectiveness of advance directives; to improve the clinical efficacy of advance directives, the researchers suggest:

• doing away with mandatory legal language to improve readability;

• expanding the potential pool of medical decision-makers to include non-medical professionals who may be close to unbefriended adults;

• promoting universal acceptance of oral advance directives;

• eliminating witness and notary requirements;

• adoption by all states of reciprocity laws for directives from other states, regardless of the location or type of planning tool used; and

• allowing patients to document their religious, social, and cultural values and preferences for end-of-life care. [FN141]

The general themes of recent advance care directive legislative initiatives can be categorized as:

• general advance care directive legislation;

• simplifying advance care directives;

• awareness of advance care directives;

• providing or withholding life-sustaining treatment; and

• the role of surrogates in end-of-life decision-making.

B. Awareness of Existence of Advance Care Directives

The creation of advance care registries can give caregivers and others the ability to verify that advanced care directives have been put into place. Measures addressing the establishment of such registries have been initiated.

A recent study explored the knowledge dementia caregivers have about advance care planning (ACP), how they learn to execute formal advance directives and how they understand their roles as decision makers for the patients. Researcher Mariette L. Klein identifies factors that contribute to the completion of an ACP process such as demographic, psychosocial, and situational factors. She found that caregivers understand ACP as having the power to shape the dying process for dementia patients; that it is not just about executing formal written ADs but how caregivers exercise that power.

For the caregivers, the process of ACP occurs along a trajectory from years before dementia, to dementia diagnosis, to end stage and death. At each of these stages, actions taken by the caregivers and their motivation are identified. Three key features of the ACP process in all three stages are examined: conversations within the family and with trusted others, gaining knowledge of ACP, and keeping ACP documents. How caregivers use ACP is based on how they define their roles as decision makers for their patients by: accepting responsibility for making difficult decisions regarding treatment for the patients, using ACP as an effective tool to shape the dying process for their patients, and doing battle with health care professionals to honor patients' wishes.

Klein concludes that some successful interventions could be adapted specifically for dementia families: Comprehensive Home-Based Options for Informed Consent about End State Services (CHOICES) for medically-fragile, home-bound older adults who do not meet criteria for the Medicare hospice benefit, and Palliative Excellence in Alzheimer Care Efforts (PEACE), a disease management model for dementia patients that includes ACP, patient-centered care, caregiver support, and palliative care.” [FN142]

C. Providing or Withholding Life-Sustaining Treatment

A recent study performed by researchers at Queen Mary University of London found that the religious views of the patient's treating physician could affect the end of life care that a patient receives. The United Kingdom study found that the physicians “who described themselves as very or extremely religious were less likely to discuss treatment options that could hasten death.” At the other end of the spectrum, physicians without strong religious beliefs were more likely to discuss all options with their patients, including providing treatment that would hasten death. The lead researcher, Dr. Clive Seale, concluded that “Physicians who deal with terminal patients at the end of life should be more aware of how their religious views affect the treatment decisions they make.” [FN143]

As reported by *The Philadelphia Inquirer*, *Kaiser Health News* has suggested that a new approach may combine palliative and hospice care to allow active treatment and end-of-life care to occur simultaneously for the terminally ill. [FN144] As opposed to standard Medicaid/ Medicare protocols stipulating that one “must give up aggressive treatment to get end-of-life counseling and care,” the new initiative, says *KHN*, “may be especially useful for people using dialysis to extend their lives, and those waiting for organ transplants that may not come in time.” In addition, “the change may encourage people with any kind of terminal illness to take advantage of hospice care earlier.” As documented by *KHN*:

The new law instructs Medicaid, the state-federal program for the poor, to cover simultaneous hospice and curative care for children with terminal illnesses immediately. And it directs the federal Medicare program, which covers seniors and disabled people, to launch up to 15 pilot projects around the country to test the concept. If the experiment is deemed successful and doesn't increase costs, then Medicare could make the benefit available to everyone in hospice.

Additionally, a panel of experts gathered by doctors from the Mayo Clinic and the Yale University School of Medicine has created guidelines for proceeding with end-of-life treatments for those who are terminally ill and have implanted defibrillators. [FN145] According to *McKnight's Long-Term Care News & Assisted Living*, the new guidelines include the following recommendations:

• All patients with implanted electronic devices are encouraged to make advance directives, and to decide on their own whether or not to remove the device.

• Adult patients should be assumed to be competent, but if they are incapacitated, a health care proxy should make a decision.

In submitting the guidelines, the panel emphasized that neither physicians nor caregivers should “be compelled to perform tasks that conflict with their ethical values.”

Odds of Reversing ICU Patients' Prior Preferences to Forgo Life-Sustaining Therapies Vary Widely Across the U.S., according to Penn Study

Intensive care units across the United States vary widely in how they manage the care of patients who have set preexisting limits on life-sustaining therapies, such as authorizing do-not-resuscitate (DNR) orders and prohibiting interventions such as feeding tubes or dialysis, according to new research from the Perelman School of Medicine at the University of Pennsylvania. [FN146] Their work is published in the current issue of *JAMA Internal Medicine*.

“We've long known that end-of-life and critical care varies across nations, regions and centers, whether from changes in local policies, practice culture or resource constraints,” said the study's lead author Joanna L. Hart, MD, MSHP, a pulmonary and critical care physician and post-doctoral research fellow at Penn. “But, we hypothesized that by looking at this specific patient population, we could attribute this variability as an appropriate response to patient preferences in care, and undue or unsupported variability. No previous studies we're aware of have analyzed variations in care for patients who, upon admission, have similar care requests.”

Hart and colleagues also sought to determine the portion of ICU patients who are admitted with existing treatment limitations ? which may have been outlined in advance directives or otherwise ordered by inpatient physician -- and how these patients are managed in the ICU.

The researchers examined a retrospective cohort of patients from 141 intensive care units in 105 hospitals, for a total of 277,693 patients from April 2001 through December 2008 and found that 4.8 percent of ICU admissions were patients with preexisting limits on care. Care limitations for most of these patients included DNR orders, which included preferences prohibiting chest compressions, intubation, and use of defibrillation to restart their hearts. Other patients had documented restrictions on acceptable therapies, ranging from dialysis to nutritional support such as feeding tubes (21 percent), and four percent expressed a preference for comfort measures only. Patients admitted with treatment limitations tended to be older than those without such limits (78 years on average) and nearly all had preexisting chronic illnesses conditions, most commonly chronic respiratory disease (14 percent), and chronic kidney disease (13 percent). Most (52 percent) of patients were admitted to the ICU from the emergency department, and 35 percent died during the hospital stay studied.

But the researchers found that these patients' preferences to refrain from use of lifesaving measures were often changed during their stay. Among all patients admitted with treatment limitations, 23 percent of patients nonetheless received CPR in the ICU, with great variability among ICUs: with less than five percent of patients at some ICUs and greater than 90 percent in other ICUs. Overall, 41 percent of patients who entered with treatment limitations received one or more forms of life support, and 18 percent had a reversal of previous treatment limitations during their ICU stay.

The researchers found that when ICU care was managed by a critical care physician, the odds were greater that the preexisting limitations on care would change and their care would be escalated with new forms of life support administered. Suburban hospitals, when compared to urban settings, were found to be associated with greater odds that patients surviving an ICU stay would receive new treatments and have new treatment limitations established during their stay.

Knowledge of Palliative Care and Less End-of-Life Disruption

(Brown University) ? When a nursing home patient is dying, aggressive interventions such as inserting a feeding tube or sending the patient to the emergency room can futilely exacerbate, rather than relieve, their distress. [FN147] Palliative care focuses nursing home resources on providing comfort at the end of life, but nursing directors vary widely in their knowledge of it. A new large national study found that the more nursing directors knew about palliative care, the lower the likelihood that their patients would experience aggressive end-of-life care.

Susan C. Miller, professor (research) of health services, policy and practice in the Brown University School of Public Health and lead author of the study in the Journal of Palliative Medicine, worked with colleagues to survey nursing directors at more than 1,900 nursing homes around the country between July 2009 and June 2010 to assess their knowledge of palliative care and their facility's implementation of key palliative care practices. The study is the first nationally representative sample of palliative care familiarity at nursing homes.

More than one in five of the surveyed directors had little or no basic palliative care knowledge (i.e., a score of 1 or 0 on a 0-to-3 scale), although 43 percent were fully versed. The average score was 2.2. Facility palliative care practice scores ranged from 12 to 36, with an average of 28.1.

In addition to quizzing the directors, the researchers also analyzed Medicare data on the 58,876 residents who died during the period to ascertain the treatments they experienced when they were dying.

When the researchers analyzed palliative care knowledge together with treatment at end of life, they found that the more directors knew about basic palliative care, the lower likelihood that nursing home patients would experience feeding tube insertion, injections, restraints, suctioning, and emergency room or other hospital trips. Meanwhile, patients in higher-knowledge homes also had a higher likelihood of having a documented six-month prognosis. Most of these associations were highly statistically significant, but a few were marginally significant even after adjusting for a variety of factors including a nursing home's extent of hospice use.

The study shows only an association between palliative care knowledge and less aggressive end-of-life care, the authors note. It could be that the knowledge leads to improved care, but it could also be that at nursing homes with better care in general, there is also greater knowledge. But if there is a causal relationship, then it could benefit thousands of nursing home residents every year for their nursing home caregivers to learn more about palliative care, the authors conclude.

Unrelated “Next of Kin” May Lead to Legal Confusion

(Reuters Health) ? When hospitalized patients list nonrelatives as next of kin, state laws might interfere with those patients' wishes ? and a new study suggests the situation isn't rare. [FN148] In **Connecticut**, where researchers looked at medical charts of nearly 110,000 hospitalized veterans, eight percent had specified someone other than a close family member as next of kin ? in conflict with the state's “default surrogate consent” laws.

Default surrogate consent statutes are designed to designate a proxy for patients who can't make their own medical decisions. In most states, spouses are given first priority, followed by adult children, parents and siblings, the authors write in a research letter in JAMA. But states are inconsistent in their recognition of other relationships, like friends, distant relatives or unmarried or same-sex partners.

In the Connecticut study, unrelated designees noted in patients' charts included “baby momma,” “common law spouse,” “live-in soul mate,” and “same-sex partner.”

Filling out an advanced directive care plan, which can be done easily online, would avoid the problem, but most people still do not do this, said Pope. Appointing a healthcare proxy or durable power of attorney may take more legal resources, but would also prevent confusion, said Dr. Andrew B. Cohen of Yale University School of Medicine in New Haven, Connecticut, who led the new study.

Cohen and his colleagues examined the next-of-kin relationships listed for 109,803 veterans who received care at Veterans Health Administration facilities in Connecticut between 2003 and 2013. Almost 93 percent listed a nuclear or immediate family member as next of kin. About 3 percent listed a more distant relative and 4 percent listed a person with no blood or legal relation, often a friend, common law spouse or same sex partner. Less than 1 percent listed other social connections, like landlady, priest, roommate, or sponsor. Six percent of veterans over age 65 and about 9 percent of those under age 65 had someone other than a nuclear family member listed as next of kin.

Quebec has a similar default consent statute, but does include a category for a person who shows special interest who is not a blood or legal relative. Adding this category to U.S. statues would solve part of the problem. The choice should not be left to the doctor, who has a conflict of interest when it comes to giving or refraining from treatment.

D. Effect of Advance Directives on Palliative Care

Researchers from the University of Michigan have found that individuals who have advance directives are more likely to receive palliative care and are less likely to die in a hospital. Medicare expenditures for enrollees with advance directives also are lower, especially in higher-spending regions of the United States, the study noted. The study is one of the first to look at national data linking end-of-life spending, treatments and advance directives. Researchers analyzed records of health and retirement study participants who died between 1998 and 2007, including their Medicare claims, and interviews were conducted with beneficiaries' next of kin. The study was published in the October 5 issue of the Journal of the American Medical Association. [FN149]

Caregivers in nursing home and hospitals may forgo palliative and comfort care for patients with “do not resuscitate” orders, a new study in Oregon suggests. “The risk is that you make assumptions about the patient because of their DNR. You assume they may not want this treatment or that treatment,” says Dr. Erik Fromme, a palliative care specialist at the Oregon Health & Science University. Fromme and his colleagues used a unique registry in Oregon to compare detailed treatment references of more than 25,000 people. Since 2009, Oregon has kept an electronic registry of preferences residents recorded with a document called Physician Orders for Life-Sustaining Treatment, or POLST. The researchers found that 18,000 people, or 72 percent of those in the registry, did not want CPR, but many wanted other treatment, including hospital care. About 55 percent wanted the option of antibiotics for infections. Nearly one-quarter considered a temporary feeding tube appropriate.

Previous studies found evidence doctors make assumptions and withhold many kinds of care beyond CPR when patients have a DNR order. Nursing home residents with DNR orders who came down with pneumonia, for example, were 30 percent less likely to be hospitalized than comparable nursing home residents with no DNR, University of Missouri researchers found. Researchers at Johns Hopkins University found a DNR order made doctors significantly less likely to order blood cultures, central lines, transfusions and other treatments when responding to hypothetical cases. [FN150]

E. Medicare Reimbursement for Physician Counseling

Reimbursement of providers for talking to Medicare patients and their families about “advance care planning” is among the recommendations to be issued by the AMA's Relative Value Scale Update Committee (RUC) to the Centers for Medicare and Medicaid Services (CMS). Every year, the AMA makes such recommendations to the CMS on a broad range of procedures and services. CMS uses these recommendations, along with input from others, to set reimbursement rates.

Counseling on advance care planning includes information on living wills and end-of-life treatment options and harkens back to an earlier provision in the Affordable Care Act. That provision was removed after former Republic vice-presidential candidate Sarah Palin accused President Obama of proposing “death panels” to determine who deserved life-sustaining medical care and the public outcry that ensued.

However, in 2016, the first year that health care providers were allowed to bill for the consultations, nearly 575,000 Medicare beneficiaries took part in conversations to discuss advance-care planning, *Kaiser Health News* reports. [FN151] Nearly 23,000 providers submitted about $93 million in charges, including more than $43 million covered by the federal program for seniors and the disabled. Use was much higher than expected, nearly double the 300,000 people the American Medical Association projected would receive the service in the first year. Still, only a fraction of eligible Medicare providers ? and patients ? have used the benefit, which pays about $86 for the first 30-minute office visit and about $75 for additional sessions.

Geriatricians, oncologists and other medical specialists who see gravely ill patients, however, say it's crucial to elicit a patient's wishes for treatment and other pastoral or psychological supports in a dire medical situation. If Medicare reimburses doctors for such discussions, as it pays them for examining patients and performing procedures, they are much more likely to happen. Some private insurers already reimburse doctors who help patients with advance care planning. Under Medicaid, states largely determine what medical services are covered, and at least two states, Oregon and Colorado, provide reimbursement for advance care planning.

Studies show that when given a choice, patients often forgo invasive procedures at the end of life. Such procedures can be costly while doing little to extend or improve the quality of the patient's life. But some people fear that end-of-life conversations could lead to rationing health care or withholding it entirely.

The AMA RUC panel is recommending specific medical codes for the reimbursement of doctors for advance care conversations. Medical codes provide a uniform description of hundreds of medical procedures and services and are used by medical providers, hospitals, and insurers across the country. Without such a code, doctors who want to have such conversations with their patients have had to squeeze them into medical appointments ostensibly held for another purpose. “You essentially have to be deceitful to get paid to do advance care planning for the patient who doesn't have a medical illness,” said Christopher A. Jones, an assistant professor of palliative care at Duke University.

F. Research Reveals What to Discuss Near End of Life

A study has identified the top five things health care teams should discuss with hospitalized patients and their families at the end of life. The research found gaps, however, between what patients would like and the care they receive. The team, led by a McMaster University researcher, with backgrounds in general internal medicine, critical care medicine and palliative care, surveyed 233 hospitalized older adults with serious illnesses and 205 family members about the importance of the 11 guideline-recommended elements of end-of-life care. The patients had been admitted to nine hospitals in British Columbia, Alberta, Ontario, and Quebec. In the

study published in the Canadian Medical Association Journal (CMAJ), seriously ill hospitalized patients and their families say the most important aspects to discuss are:

• Preferences for care in the event of life-threatening illness

• Patient values

• Prognosis of illness

• Fears or concerns

• Additional questions regarding care.

“However, we found that these elements are infrequently discussed and that concordance between preferred and prescribed goals of care is low,” the authors stated. Current guidelines list 11 key elements for health care providers to discuss regarding end-of-life care that are based mainly on expert opinion, and not on patient and family feedback. [FN152]

G. California: End-of-Life Care Orders

A study conducted by UCLA finds broad acceptance of written end-of-life care orders among California nursing home residents, with nearly half completing a Physician Orders for Life-Sustaining Treatment, or POLST, form in 2011. Published in the *Journal of General Internal Medicine*, found no difference in completion of the form by race or ethnicity, suggesting wide acceptance of these orders among California's highly diverse population. The researchers did, however, identify a few areas where the use of the forms in nursing homes could be improved.

The POLST document records a patient's end-of-life care preferences regarding cardiopulmonary resuscitation, aggressiveness of medical interventions and artificial nutrition. Printed on bright pink paper, and signed by the patient as well as a doctor, nurse practitioner or physician assistant, the form is designed to travel with a patient to different care settings, such as hospitals, nursing homes, or doctor's offices. It was enacted for use in California through AB 3000 legislation in 2009. Completion of the order by the individual is voluntary.

This is the first study of a life-sustaining treatment form using the Long-Term Care Minimum Data Set, or MDS, a federally mandated clinical assessment of all residents in nursing homes certified by Medicare or Medicaid. To date, California is the only state to have added questions about completion of the orders to the data set.

“The broad adoption of POLST in California's nursing homes is possible due to a combination of state-level efforts?such as passing legislation and developing a standardized POLST form and curriculum?and the grassroots efforts of local POLST coalitions who educate providers and consumers in cities and counties throughout the state,” said Judy Thomas, study co-author and CEO of the Coalition for Compassionate Care of California, the organization that runs the POLST program in California. “Analysis of the MDS data confirms the effectiveness of grassroots outreach efforts, and will also help us focus on the facilities or communities in need of additional support to ensure best practices are being followed for POLST implementation.” [FN153]

H. App Helps Ease Access to Advance Directive Documents

An application that aims to make patients' end-of-life plans easy to access for healthcare providers and family members is among the winners of the Department of Health and Human Services' “Move Health Data Forward Challenge.” The program, “Live and Leave Well,” allows consumers to develop and securely share their end-of-life plans with caregivers and healthcare providers and walks users through the process of developing advance medical directives. It allows them to complete a Do Not Resuscitate (DNR) order and Medical Orders of Life Sustaining Treatment (MOLST), as well as healthcare proxy forms directly on the platform. The documents can then be shared with family, friends and healthcare providers, as well as emergency medical workers. [FN154]

I. Noncompliance with DNR

The state of New York has faulted a Syracuse nursing home for performing cardiopulmonary resuscitation on a resident even though she had a do-not-resuscitate order on file. The DNR stated that she did not want to be resuscitated or intubated, wanted limited medical interventions, and wished to be sent to the hospital only if necessary. When she was found not breathing, unresponsive, and without a pulse, nurses took all those emergency actions before realizing that the resident's chart contained the DNR order. According to the state inspection report, the nurse who called for help after finding the woman unresponsive said she was never trained how to determine if a resident has a DNR order. The nursing home said it would educate nurses on how to determine if a resident has a DNR order or other advance directives. [FN155]

J. New York Advance Directive Would Let Dementia Patients Refuse Food

A New York end-of-life agency has approved a new document that lets people stipulate in advance that they don't want food or water if they develop severe dementia. Finalized in March, the directive aims to provide patients a way to hasten death in late-stage dementia, if they so choose. Although dementia is a terminal illness, it isn't a condition covered by the laws in the seven U.S. jurisdictions that allow medical aid-in-dying. Increasingly, patients are seeking other options, said Dr. Timothy Quill, a palliative care expert at the University of Rochester School of Medicine and longtime advocate of the practice.

The document offers two options: one that requests “comfort feeding” (providing oral food and water if a patient appears to enjoy or allows it during the final stages of the disease) and one that would halt all assisted eating and drinking, even if a patient seems willing to accept it.

Supporters say it's the strongest effort to date to allow people who want to avoid the ravages of advanced dementia to make their final wishes known ? while they still have the ability to do so. But critics say it's a disturbing effort to allow withdrawal of basic sustenance from the most vulnerable in society. [FN156]

K. Simon's Law

In 2010, Simon Crosier was diagnosed at birth with “Trisomy 18,” also known as Edward's syndrome. The condition is considered a “lethal” anomaly and “incompatible with life.” After that clinical diagnosis, Simon's care and treatment began to be withheld, but the extent of the hospital's denial of care would not be known to his parents until after he died. [FN157] After Simon passed away, his parents found out that because of Simon's medical condition a do-not-resuscitate (DNR) order had been placed on his medical file, and that the medical staff had only been feeding him drops of sucrose. All of this without their knowledge.

Legislative efforts designed to guarantee parents their inalienable right to participate in the healthcare decisions of their disabled or severely ill children are supported by a number of pediatric and bioethic groups, including the American College of Pediatricians. Once inconceivable, the practice of hospital staff placing a Do Not Resuscitate (DNR) order on a child's chart, without the informed consent of the child's parents or legal guardian, is on the rise. “It is first and foremost a physician's job to offer medical facts together with hope, and over time, if hope for survival becomes unwarranted, then physicians should discuss and reach understandings with the family regarding prognosis and interventions. This is how the doctor-patient relationship should proceed in all pediatric cases; this is what Simon's Law will codify. All states are encouraged to adopt similar legislation.” [FN158]

Dubbed “Simon's Law,” **Kansas** was the first to enact legislation, in 2017, that prevents doctors from putting do-not-resuscitate orders in children's medical charts without parental notification. The law also requires hospitals to give parents and prospective patients access to its denial of care policies, sometimes referred to as futility policies. Arizona**,** Missouri**, and** New Mexico**, are considering similar legislation.**

L. Training Program for Nursing Facilities

After a successful pilot, a training program that helps nursing homes offer advance care planning support is expanding to more than 170 nursing facilities across the country. [FN159] Led by Regenstrief Institute and Indiana University researchers, the program designed to provide support for residents with Alzheimer's disease and their family members. The National Institute on Aging announced an expected award of $3 million for the next phase of research. Regenstrief and Indiana University scientists led a team in developing an intervention called the Advance Care Specialist Program. The program specially trains members of the nursing facility staff to educate other employees and implement procedures to support advance care planning for people living in the facility. The research team worked collaboratively with leaders from three partner companies who own and run nursing facilities to create and refine this program.

Advance care planning involves discussions with patients and their families about goals, values, and treatment preferences. For example, one patient might prefer to avoid transfers to the hospital to focus on comfort, whereas another may want all available interventions with the goal of extending life as long as possible. Once these preferences are discussed, they will be formalized in documents such as the POLST form that can help ensure future treatment is in line with their preferences.

This second phase of the APPROACHES (Aligning Patient Preferences?a Role Offering Alzheimer's patients, Caregivers, and Healthcare providers Education and Support) project, will randomly assign approximately 170 nursing facilities to either implement the program or continue with their normal procedure. A corporate implementation champion will oversee the roll-out and be the primary point of contact for the ACP specialist. The training modules for the ACP specialists are available online and integrated with the nursing facilities' systems. The program is designed to be scalable.

M. Recent Legislative Activity

Federal

2019 CONG US HR 5582, introduced January 10, 2020, and 2019 CONG US S 3138, introduced December 19, 2019, would require hospitals and certain other participating providers under Medicaid or the Children's Health Insurance Program to disclose the provider's policy on parental consent for the provision, withdrawal, or denial of life-sustaining treatment for minors, and for other purposes.

Alabama

2020 AL S.B. 153 (NS), engrossed on March 5, 2020, would require doctors to obtain consent of parent or legal guardian of minor prior to entering ‘do not attempt resuscitation order’ order.

Arizona

2020 AZ H.B. 2260 (NS), engrossed on February 27, 2020, providing for training and policies regarding cardiopulmonary resuscitation in health care institutions that provide congregant or residential care.

Florida

• 2020 FL H.B. 709 (NS), amended/substituted February 3, 2020, would provide that a guardian may only consent to or authorize do-not-resuscitate order with court approval.

• 2020 FL S.B. 994 (NS), amended/substituted January 28, 2020, expanding factors for a court to consider when appointing a guardian; prohibiting a guardian from consenting to or signing on behalf of a ward an order not to resuscitate without court approval; prohibiting guardians from taking certain actions on behalf of an alleged incapacitated person or minor, etc.

Hawaii

2019 HI S.B. 3047 (NS), introduced January 23, 2020, would allow an advance directive to be a valid written request for a prescription to be self-administered for the purpose of ending an adult's life; would include advanced practice registered nurses under the definition of 'attending provider'; would allow an attending provider to waive the counseling referral requirement; would allow an attending provider to perform duties through telehealth, under certain conditions; and would require health insurance policies and contracts issued after December 31, 2020, to provide coverage for services related to ending a patient's life.

Idaho

• 2020 ID H.B. 578 (NS), introduced on March 2, 2020, would establish Simon's Law, regarding life-sustaining treatment for unemancipated minors.

• 2020 ID H.B. 519 (NS), introduced February 18, 2020, would add to existing law to implement Simon's Law, regarding life-sustaining treatment for child patients.

Illinois

• 2019 IL S.B. 182 (NS), filed January 30, 2019, would provide for the Department of Public Health to study the feasibility of creating a statewide registry of advance directives and Practitioner Order for Life-Sustaining Treatment forms; Provides that various types of documents may be in hard copy or electronic format.

• 2019 IL S.B. 3524 (NS), introduced February 14, 2020, would amend the Health Care Surrogate Act; change certain uses of the term 'qualified physician' to 'qualified health care practitioner'; provide that before voiding or revoking a uniform practitioner orders for life-sustaining treatment (POLST) form, National POLST form, or another state's POLST Paradigm portable medical orders form consented to by the individual, that individual's legally authorized surrogate decision maker shall first: engage in consultation with the attending health care practitioner; consult the patient's advance directive, if available; and make a good faith effort to act consistently, at all times, with the patient's known wishes, or, if the patient's wishes are not known, using substituted judgment as the standard; provide that a health care provider facility shall comply with a POLST form, National POLST form, another state's POLST Paradigm portable medical orders form, or an out-of-hospital Do Not Resuscitate (DNR) order sanctioned by a State in the United States that: has been executed by an adult; and is apparent and immediately available.

Indiana

2020 IN H.B. 1317 (NS), engrossed January 30, 2020, would allow an individual to make a health care advance directive that gives instructions or expresses preferences or desires concerning any aspect of the individual's health care or health information and to designate a health care representative to make health care decisions and receive health information for the individual; consolidate definitions of 'life prolonging procedures'; require the state department of health to prepare a sample advance directive; provide that the appointment of a representative or attorney in fact to consent to health care that was legally executed before January 1, 2023, is valid as executed.

Michigan

• 2019 MI H.B. 5417 (NS), engrossed May 19, 2020, would allow a parent or guardian to execute a do-not-resuscitate order on behalf of a minor child.

• 2019 MI H.B. 5418 (NS), engrossed May 19, 2020, would require filing, storage, and notice rules regarding do-not-resuscitate orders and comfort or care plans and limit of liability for providing these measures.

• 2019 MI H.B. 5419 (NS), engrossed May 19, 2020, would authorize a guardian of a minor to execute a do-not-resuscitate order on behalf of the ward.

• 2019 MI H.B. 5476 (NS), introduced February 11, 2020, regarding patient directives; providing procedures for withholding certain life-sustaining treatments for a minor.

Minnesota

• 2019 MN S.F. 555 (NS), introduced January 28, 2019, would provide for an advance care planning resource organization grant.

• 2019 MN S.F. 2609 (NS), introduced March 20, 2019, would provide an appropriation for advance care planning on end-of-life care choices.

• 2019 MN S.F. 3625 (NS), engrossed March 12, 2020, providing appropriation for advance care planning on end-of-life care choices.

Missouri

• 2020 MO H.B. 2493 (NS), introduced February 18, 2020, would add provisions relating to outside the hospital do-not-resuscitate orders from another state, the District of Columbia, or a territory of the United States.

• 2020 MO S.B. 1010(NS), introduced February 17, 2020, would modify provisions relating to outside the hospital do-not-resuscitate orders.

Nebraska

• 2019 NE L.B. 365 (NS), introduced January 16, 2019, would adopt the Health Care Directives Registry Act.

• 2019 NE L.R. 191 (NS), introduced May 21, 2019, provides for an interim study to evaluate the potential use of Physicians Orders for Life-Sustaining Treatment and the potential use of out-of-hospital Do Not Resuscitate protocols.

New Hampshire

• 2019 NH H.B. 1659 (NS), introduced January 8, 2020, would allow a mentally competent person who is 18 years of age or older and who has been diagnosed as having a terminal disease by the patient's attending physician and a consulting physician, to request a prescription for medication which will enable the patient to control the time, place, and manner of such patients death. Under this bill, the request is witnessed and signed in essentially the same manner as an advance directive. The bill also requires the division of public health services, department of health and human services, to collect certain information and compile a statistical analysis of such information.

• 2019 NH S.B. 598 (NS), amended/substituted on March 5, 2020, would add physician assistants to the law governing advance directives.

New Jersey

2020 NJ A.B. 2472 (NS), introduced February 3, 2020, concerning Practitioner Orders for Life-Sustaining Treatment forms.

New Mexico

2020 NM H.B. 132 (NS), introduced January 23, 2020, would amend the Uniform Health-Care Decisions Act relating to orders not to resuscitate for unemancipated minors.

New York

• 2019 NY A.B. 1089 (NS), introduced January 14, 2019, relating to health care proxy information on driver's licenses.

• 2019 NY A.B. 1203 (NS), introduced January 14, 2019, would restore medical futility as a basis for DNR.

• 2019 NY A.B. 2194 (NS), introduced January 22, 2019, would establish do not resuscitate orders on drivers' licenses and identification cards.

• 2019 NY A.B. 5973 (NS), introduced February 22, 2019, would make technical, minor and coordinating amendments regarding health care agents and proxies, decisions under the family health care decisions act, and nonhospital orders not to resuscitate.

• 2019 NY S.B. 2653 (NS), introduced January 28, 2019, would establish do-not-resuscitate orders on drivers' licenses and identification cards.

• 2019 NY S.B. 4841 (NS), introduced March 27, 2019, would permit the execution of orders not to resuscitate and orders pertaining to life sustaining treatments by physician assistants.

• 2019 NY S.B. 5940 (NS), introduced May 16, 2019, relating to health care agents and proxies, decisions under the Family Health Care Decisions Act and non-hospital orders not to resuscitate.

North Carolina

2019 NC S.B. 163 (NS), introduced February 28, 2019, requiring parental notification and agreement prior to issuing an order to withhold cardiopulmonary resuscitation and other life-prolonging measures from patients who are unemancipated minors.

Ohio

2019 OH H.B. 692 (NS), introduced June 8, 2020, to expand the laws on wills, declarations or living wills, durable powers of attorney for health care, and transfer on death designation affidavits by providing for their execution electronically.

Oklahoma

2020 OK H.B. 2588 (NS), adopted May 18, 2020, would limit the powers of a guardian to consent on behalf of the ward to the withholding or withdrawal of life-sustaining procedures as provided in the Oklahoma Advance Directive Act.

Oregon

2020 OR S.B. 1606 (NS), adopted July 7, 2020, prohibits a hospital from conditioning treatment on a patient having a POLST, advance directive, or any instruction relating to the administration, withholding or withdrawing of life-sustaining procedures or artificially administered nutrition and hydration.

Pennsylvania

• 2019 PA H.B. 987 (NS), introduced March 27, 2019, in living wills, further providing for emergency medical services; in out-of-hospital nonresuscitation, further providing for definitions, orders, bracelets and necklaces, revocation, and for emergency medical services, repealing provisions relating to advisory committee and providing for discontinuance; and providing for Pennsylvania orders for life-sustaining treatment.

• 2019 PA H.B. 2111 (NS), introduced December 9, 2019, would provide for do-not-resuscitate orders for minors.

• 2019 S.B. 187 (NS), introduced February 1, 2019, providing for when a living will is operative, for revocation and authority of health care agent, and for living will and other advance care directives registry.

South Carolina

• 2019 SC H.B. 5107 (NS), introduced February 5, 2020, relating to do-not-resuscitate orders, to allow a parent or legal guardian of a medically eligible child to request and revoke a do not resuscitate order for emergency services for the child.

• 2019 SC S.B. 132 (NS), amended/substituted March 20, 2019, would provide that a physician assistant may issue an order for a patient to receive services from a licensed hospice, and execute a do-not-resuscitate order.

• 2019 SC S.B. 1147 (NS), introduced March 4, 2020, relating to do-not-resuscitate orders, to allow a parent or legal guardian of a medically eligible child to request and revoke a do-not-resuscitate order for emergency services for the child.

Vermont

2019 VT H.B. 950 (NS), adopted June 15, 2020, allowing remote witnesses for advance directives for a limited time in response to the COVID-19 pandemic.

Virginia

2020 VA H.B. 362 (NS), adopted March 2, 2020, expands the class of health care practitioners who can make the determination that a patient is incapable of making informed decisions to include a licensed physician assistant. The measure also provides that such determination shall be made in writing following an in-person examination of the person and certified by the physician assistant.

Washington

2019 WA H.B. 1175 (NS), engrossed February 14, 2019, relating to the authorization of health care decisions by an individual or designated person.

West Virginia

• 2019 WV H.B. 2493 (NS), introduced January 17, 2019, and 2019 WV S.B. 307 (NS), introduced January 15, 2019, creating the Nondiscrimination in Involuntary Denial of Treatment Act, requiring the provision of medical treatment under certain circumstances, requiring the disclosure of policies related to the life-preserving treatment a patient may receive or be denied, and requiring the Department of Health and Human Resources to maintain and report on certain information.

• 2019 WV H.B. 2788 (NS), introduced January 31, 2019, relating to life-sustaining treatment policies of health care facilities.

• 2020 WV S.B. 605 (NS), introduced January 23, 2020, and 2020 WV H.B. 4391 (NS), introduced January 16, 2020, relating to health care decisions: amending definitions, including redefining the definition of ‘life-prolonging intervention’ and forms of a living will or medical power of attorney or combined medical power of attorney and living will.

• 2019 WV S.B. 642 (NS), introduced February 18, 2019, relating to providing options in living wills, and combined medical powers of attorney and living wills, that permit the principal to either be provided with medically assisted food and fluids or not to be provided with medically assisted food and fluids if the principal is unable to communicate his or her desires.

• 2020 WV S.B. 647 (NS), adopted March 25, 2020, permitting physician's assistants and advanced practice registered nurses to issue do-not-resuscitate orders.

Wisconsin

• 2019 WI A.B. 83 (NS), introduced March 19, 2019, and 2019 WI S.B. 93 (NS), introduced March 15, 2019, authorizing creation and implementation of an advance directive registry and granting rule-making authority.

• 2019 WI A.B. 287 (NS), adopted February 5, 2020, regarding certifications for advance directives and findings of incapacity related to powers of attorney for health care.

• 2019 WI A.B. 757 (NS), introduced January 21, , would allow do-not-resuscitate necklaces or pendants, require the exercise of rule-making authority, and provide a penalty.

• 2019 WI S.B. 254 (NS), introduced May 30, 2019, regarding certifications for advance directives and findings of incapacity related to powers of attorney for health care.

VI. PALLIATIVE CARE

“Palliative care” may be described as care that seeks to treat symptoms and improve the quality of life in patients with cancer and other serious illnesses. [FN160] Palliative care adapts aspects of the hospice philosophy without requiring patients to forgo curative care or to have a life expectancy of six months or less. [FN161]

About a third of U.S. hospitals now offer some form of palliative care. The main goal of palliative care is to improve a patient's quality of life, but palliative care may also keep hospital costs down. *U.S. News & World Report* highlighted a study published in 2008 in the *Archives of Internal Medicine* which found that hospitals with palliative care programs in place saved $279 to $374 per day on patients and up to $1,700 to $4,900 overall per admission. [FN162] The savings occurred as a result of reductions in pharmacy, laboratory and intensive care costs as expenditures in these areas were often lessened or eliminated by hospitals with fully operative palliative care units. The NHPCO recently signaled the need for increased palliative care access in critical care settings. Declaring that “[m]ore than one out of five deaths in the United States occur during or following admission to an Intensive Care Unit,” [FN163] the organization issued a call to action based on its concern for “patients overwhelmed with symptoms such as pain, difficulty breathing, or confusion, and families of patients in the ICU [who] must oftentimes address difficult medical decisions.”

According to a recent report by the nonprofit economic research group Florida TaxWatch, palliative care could reduce health care costs by $103 billion within the next 20 years. [FN164] The group recommended that policymakers take action to expand palliative care utilization in the state. In general, palliative care can reduce health care costs by more than $4,000 per patient, a July 2017 study in *Health Affairs* **[FN165]** found. It can also reduce the frequency of 911 calls, emergency department visits, and unnecessary hospitalizations. Many hospice providers offer palliative care in addition to their other services. Payors often treat it as a precursor to hospice, allowing patients to receive similar services until they become eligible for the hospice benefit.

The Florida TaxWatch report identified barriers to expanding palliative care in the state, including financial stability for providers and lack of service reimbursement systems, lack of public awareness, workforce shortages, professional education and training deficiencies, and regulatory barriers. The group called on legislators and regulators to establish a regulatory framework that would include a standardized definition for palliative care, minimum standards of available services that are consistent with national standards, and a re-examination of payment models. While the report was specific to Florida, its recommendations echo conversations occurring at the national level. Congress is considering legislation to boost the palliative care workforce, and to date 25 states have passed legislation to promote palliative care utilization.

As the U.S. population ages and develops more illnesses, the need for palliative care is predicted to become increasingly important. Hospital care “for an increasing number of people with cancer, heart disease, kidney failure and other serious health problems,” [FN166] will likely involve better-coordinated programs with goals of improving pain management. Dr. Timothy E. Quill, director of the University of Rochester's palliative care program, perceives a general trend toward the increased acceptance of various alternatives to be considered by terminally ill patients in their last days. [FN167] Quill, a recognized expert in end-of-life issues, also maintains, along with others in the field, that every terminally ill patient should have access to palliative care for pain management and emotional support. In addition, he recommends a mandatory palliative care consultation as part of end-of-life care as a means of mediating treatments of “last resort,” such as overly aggressive medicating for pain or the premature invoking of advance care directives. *Medical News TODAY* reported in 2010 that research grants in the amount of $1.8 million have been awarded to 12 recipients by The American Cancer Society and the National Palliative Care Research Center (NPCRC) for palliative care studies slated to take place over the next two years. [FN168] The grants, says *Medical News TODAY*, “have brought much-needed research dollars to a field that has become an increasingly important part of patient care, but for which federal funding has been inadequate.”

A case study undertaken at The Lillian and Benjamin Hertzberg Palliative Care Institute at the Mount Sinai Medical Center in New York City pointed to more successful outcomes for a sizable number of patients and an increased number of referrals from physicians requesting “palliative care consultations earlier in their patients' hospital stay,” The Commonwealth Fund has documented. [FN169] Median Karnofsky scores (measuring perfect health at 100 to death at zero) rose ten points on average in patients at the hospital “from about 20 in 2002?2004 to about 30 in 2005?2007,” data from the Palliative Care Institute showed. Further, percentages of patients reporting moderate to severe pain dropped significantly: from 32 percent to just 5.5 percent. Based on the study, statisticians found that early referrals?as well as an increase in the overall number of referrals?suggested “that palliative care consultations have been shown to lead to improvements in multiple symptoms.”

According to a 2010 study published in the New England Journal of Medicine, the addition of palliative care as part of a patient's treatment improves the patient's quality and length of life. The study focused on 151 patients who had recently been diagnosed with advanced lung cancer. The patients who received palliative care visits at least monthly “scored higher on quality-of-life measures, experienced less depression and lived almost three months longer on average than their counterparts who received only standard cancer care.” While more clinical trials are needed, one lesson from this trial is that medical care and palliative care should be performed in conjunction with each other. [FN170]

Kaiser Health News reports on a study released February 2, 2015, in the Annals of Internal Medicine, which found the number of Americans experiencing pain in the last year of life increased by nearly 12 percent between 1998 and 2010. [FN171] This was true “even

though guidelines and quality measures for end-of-life care were developed, the number of palliative care programs rose, and hospice use doubled between 2000 and 2009." The study looked at three indicators ? pain, depression, or periodic confusion ? in 7,204 patients who died while enrolled in the national Health and Retirement study. Information was gathered through interviews with family members.

In 2017, researchers in Canada found that in the six months before death, 60% of nursing home residents without severe cognitive impairment experienced consistently low pain; 34.6% reported either moderate to severe pain, or significant increases in pain during this time, and only 5.3% experienced any degree of pain improvement. The researchers concluded that although a majority of nursing home residents experienced consistently low or improved pain levels in their last 6 months of life, a substantial number experienced consistently high or substantially worsening pain levels during this same time period. These results highlight the need to better manage pain levels for some nursing home residents during this important time. The study was conducted by researchers from the University of Manitoba, the University of British Columbia, and the University of Alberta and was published online in *JAMDA*. [FN172]

In 2021, hospice and palliative care will be offered by 53 Medicare Advantage plans in 2021 through the value-based insurance design (VBID) model, according to CMS. Payers and hospice providers will have the option to participate in a demonstration project in 2021 (referred to as the 'Medicare Advantage hospice carve-in'), to test the inclusion of hospice in VBID. The carve-in will begin at a time when Medicare Advantage premiums have dropped significantly, despite expanding benefits, even as the number of beneficiaries increases nationwide. [FN173]

A. Medical Marijuana

A patient's right to pain care medication, the degree to which physicians may prescribe pain care medication, the types of pain care medication that a state will legalize, and protecting caregivers from liability for administering palliative care all present ethical concerns for lawmakers. Consequently, the legalization of marijuana for palliative care has been a controversial issue in recent years, although more and more states have adopted laws permitting medical use. At the end of 2018, 33 states have enacted laws to legalize medical marijuana.

Issues arise when patients who are using medical marijuana are no longer able to live alone and must move to a nursing home or other assisted living facility. Many facilities receive federal funding (Medicaid). Administrators are faced with a dilemma: can they comply with federal law, which prohibits use of marijuana, while permitting residents to continue using medical marijuana? Unfortunately, the federal government has yet to address this problem. These are just some of the numerous issues that arise when medical marijuana patients become residents of these facilities. [FN174]

Marijuana remains classified as a "Schedule I" drug under the Controlled Substances Act of 1970, meaning the federal government considers it to have high potential for abuse and no accepted medical value. The Controlled Substances Act says the attorney general may "remove any drug or other substance from the schedules if he finds that the drug or other substance does not meet the requirements for inclusion in any schedule," the letter argues. If a substance is banned by international treaties ? as marijuana is ? the law grants the attorney general the power to place it "under the schedule he deems most appropriate." President Obama, however, maintained that "what is and isn't a Schedule I narcotic is a job for Congress.... It's not something by ourselves that we start changing. No, there are laws under?undergirding those determinations." Marijuana advocacy groups quickly released statements supporting the request. [FN175]

Recent Legislative Actions

Federal

• 2019 CONG US HR 647, engrossed in House on October 30, 2019, the Palliative Care and Hospice Education and Training Act would increase the number of permanent faculty in palliative care at accredited allopathic and osteopathic medical schools, nursing schools, social work schools, and other programs, including physician assistant education programs, to promote education and research in palliative care and hospice, and to support the development of faculty careers in academic palliative medicine.

• 2019 CONG US S 1921, introduced June 20, 2019, would provide that primary care services provided by the National Health Service Corps may include palliative care services.

• 2019 CONG US S 2080, introduced July 10, 2019, would increase the number of permanent faculty in palliative care at accredited allopathic and osteopathic medical schools, nursing schools, social work schools, and other programs, including physician assistant education programs, to promote education and research in palliative care and hospice, and to support the development of faculty careers in academic palliative medicine.

California

2019 CA S.B. 305 (NS), enrolled on September 13, 2019, the Compassionate Access to Medical Cannabis Act or Ryan's Law, would prohibit specified types of health care facilities from prohibiting or interfering with a terminally ill patient's use of medical cannabis within the health care facility, subject to certain restrictions. The bill would require a patient to provide the health care facility with a copy of their medical marijuana card or written documentation that the use of medical cannabis is recommended by a physician. The bill would authorize a health care facility to reasonably restrict the manner in which a patient stores and uses medical cannabis to ensure the safety of other patients, guests, and employees of the health care facility, compliance with other state laws, and the safe operations of

the health care facility. The bill would prohibit the department that licenses the health care facility from enforcing these provisions, and compliance with the bill would not be a condition for obtaining, retaining, or renewing a license as a health care facility. The bill would authorize a health care facility to suspend compliance with these provisions if a regulatory agency, the United States Department of Justice, or the federal Centers for Medicare and Medicaid Services takes specified actions, including initiating an enforcement action against a health care facility related to the facility's compliance with a state-regulated medical marijuana program. The measure was vetoed by the governor on October 12, 2019; consideration of the veto is pending in the Senate.

Hawaii

• 2019 HI H.B. 665 (NS), amended/substituted April 25, 2019, specifies that a health care provider shall not be required to consult the electronic prescription accountability system for patients when the prescription will be directly administered under the supervision of a health care provider, provided that the system is consulted when the patients are initially admitted at a hospital, for patients in post-operative care with a prescription limited to a three-day supply, or for patients with a terminal disease receiving hospice or other palliative care.

• 2019 HI S.B. 804 (NS), amended/substituted March 15, 2019, would establish the culturally competent palliative care pilot program to promote palliative care, gather health care utilization data, and conduct bidding for at least two pilot programs for home- or community-based palliative care, one of which must be located in a county with less than two hundred thousand residents. The bill would also establish an advisory group to oversee implementation of the pilot program.

Indiana

2020 IN S.B. 103 (NS), introduced January 6, 2020, would create a defense to possession of paraphernalia that: (1) the paraphernalia is for use with marijuana; and (2) a physician has certified in writing that the person suffers from a terminal illness or serious untreatable disease, and, in the professional opinion of the physician, the benefits of treatment with marijuana are greater than the risks; would create a defense to possession of marijuana that: (1) the person possessed less than two ounces of marijuana; and (2) a physician has certified in writing that the person suffers from a terminal illness or serious untreatable disease, and, in the professional opinion of the physician, the benefits of treatment with marijuana are greater than the risks.

Kansas

2017 KS S.B. 155 (NS), introduced February 3, 2017, would enact the Cannabis Compassion and Care Act providing for the legal use of cannabis for certain debilitating medical conditions.

Mississippi

• 2020 MS H.B. 1338 (NS), introduced February 17, 2020, to bring forward the “right to try act” that authorizes licensed physicians to prescribe or recommend certain investigational drugs, biological products or devices to certain eligible terminally ill patients, for the purpose of possible amendment; to bring forward section 73-25-37, which provides civil immunity to licensed physicians who prescribe or make recommendation to eligible patients regarding prescription for or treatment with an investigational drug, biological product or device, for the purpose of possible amendment.

• 2020 MS S.B. 2830 (NS), introduced February 17, 2020, would amend the “right to try act” to include those patients with a traumatic injury; to revise the definition of ‘investigational drug, biological product or device’ to include adult autologous mesenchymal stem cell.

New Hampshire

• 2019 NH H.B. 291 (NS), amended/substituted May 15, 2019, establishing a committee to study certain findings regarding hospice and palliative care.

New Jersey

2020 NJ A.B. 1635 (NS) and 2020 NJ S.B. 619 (NS), introduced January 14, 2020, would permit authorization for dispensation of medical marijuana through telemedicine and telehealth under certain circumstances.

New York

• 2017 NY A.B. 8598 (NS), introduced July 10, 2017, would provide that medical marihuana made be used for a condition, or symptom or complication of the condition or its treatment, for which, in the practitioner's professional opinion and review of past treatments, the patient is likely to receive therapeutic or palliative benefit from primary or adjunctive treatment.

• 2019 NY S.B. 4582 (NS), introduced March 15, 2019, conforming the definition of palliative care under hospice provisions to be the same as under other public health law provisions.

Rhode Island

• 2019 RI H.B. 7266 (NS), introduced January 23, 2020, would create the ‘Neil Fachon Terminally Ill Patients' Right To Try Act of 2020,’ to establish conditions for the use of experimental treatments for terminally ill patients.

• 2019 RI H.B. 7910 (NS), introduced on February 26, 2020, would create the Terminally Ill Patients' Right to Try Act of 2020, establishing the conditions for the use of experimental treatments for terminally ill patients.

Virginia

2020 VA S.B. 185 (NS), adopted April 7, 2020, allows nursing home, assisted living facility, hospice program, and hospice facility employees and staff members who are authorized to possess, distribute, or administer medications to residents to store, dispense, or administer cannabidiol oil or THC-A oil to a resident who has been issued a valid written certification for such medication.

B. End-of-Life Care Guidelines

The American College of Physicians (ACP) released updated guidelines addressing the three most common end-of-life (EOL) symptoms: pain, difficulty breathing, and depression. [FN176] According to *Drug Week*, the ACP recommended that 1) clinicians should regularly assess people with serious illness at the end of life for these symptoms; 2) clinicians should use proven therapies to treat these conditions; and 3) clinicians should ensure that advanced care planning occurs for all patients with serious illness. Drug treatment recommendations for relieving symptoms were also included in the newly released directives. As reported by *Drug Week*, "[a]ll of the ACP recommendations on EOL care are considered strong recommendations, meaning that benefits clearly outweigh the risks."

The National Consensus Project for Quality Palliative Care has released *The Clinical Practice Guidelines for Quality Palliative Care*, 4th edition, which seeks "to improve access to quality palliative care for all people with serious illness regardless of setting, diagnosis, prognosis, or age." [FN177] The NCP Guidelines are intended to encourage and guide health care organizations and clinicians, including non-palliative care specialists, across the care continuum to integrate palliative care principles and best practices into their routine assessment and care of all seriously ill patients. Importantly, the NCP Guidelines formalize and delineate available evidence-based processes and practices as well as consensus recommendations for the provision of safe and reliable high-quality palliative care for adults, children, and families with serious illness in all care settings.

Specifically, the purpose of the 4th edition is to promote access to quality palliative care, foster consistent standards and criteria, and encourage continuity of palliative care across settings. Because there is shared responsibility for delivery and quality of palliative care across health care settings and over time, the emphasis is on collaborative partnerships within and between all care providers to ensure access, quality, and continuity of palliative care.

This revision addresses best practices for both palliative care specialists, as well as all clinicians who care for people with serious illness, according to the Foreword. The expectation is that other clinicians caring for seriously ill patients will integrate palliative care competencies (such as safe and effective pain and symptom management, and expert communication skills) in their practice and palliative care specialists will provide expertise for those with the most complex needs.

The 4th edition, therefore, is intended for specialty hospice and palliative care practitioners and teams, as well as health systems, primary care and specialist physician practices, cancer centers, dialysis units, long-term care facilities, assisted living facilities, Veterans Health Administration providers, home health and hospice agencies, prisons, and other care providers. The Guidelines are also applicable to social service agencies, homeless shelters, and any other community organizations serving seriously ill individuals.

As stated in the guidelines, "[m]ost importantly, the goal of the NCP Guidelines is to improve the care that patients and families receive by defining and supporting access to high-quality palliative care in all care settings." All practitioners are encouraged to use the NCP Guidelines to strengthen knowledge and skills to better meet the needs of people living with serious illness.

The guidelines also seek to improve continuity and coordination of care and, as a consequence, reduce expenses related to duplicative or non-beneficial interventions or waste. While hospital-based palliative care and hospice are widely available in the United States, access to palliative care in other settings is often unavailable. Reliable access to palliative care in community-based settings is essential to the delivery of expert care and symptom management, as well as psychological, practical, and social support, helping patients and families remain safely in their care setting of choice, according to the guidelines.

New community-based palliative care models are meeting the needs of those with a serious illness who are neither hospitalized nor hospice-eligible, through provision of care in patient homes, physician offices/clinics, cancer centers, dialysis units, assisted and long-term care facilities, and other community settings. Community-based palliative care services are delivered by clinicians in primary care and specialty care practices (such as oncologists), as well as home-based medical practices, private companies, home health agencies, hospices, and health systems.

The guidelines were developed by the National Consensus Project for Quality Palliative Care, comprised of 16 national organizations with extensive expertise in palliative care and hospice. The Fourth Edition was endorsed and supported by more than 80 national organizations.

Published in 2013, the Third Edition called for palliative care to follow the care coordination and quality improvement processes mandated by the Affordable Care Act. The changes were decided through a "consensus process" involving leading hospice and palliative care organizations. The ACA's delivery and payment models opened the way for hospice and palliative care providers to join accountable care organizations and bundled payment groups, and so best practices should be followed to promote palliative care across all settings, the guidelines say. Providers also should institute quality assessment and performance improvement (QAPI) reviews as part of an "ongoing data driven process" to improve outcomes, according to the guidelines. The guidelines also revised and expanded the psychological and psychiatric aspects of care, including a new section on bereavement programs. [FN178]

NAHC Releases Palliative Care White Paper

The National Association for Home Care & Hospice (NAHC) and its affiliates released a whitepaper on palliative care on July 6, 2015. The whitepaper is “intended to share concepts and experiences for providers who desire to explore and develop their own [palliative care] program.” [FN179] In the absence of clear definitions and state regulations, providers who want to develop palliative care programs are faced with opportunities and challenges.

C. Defining “Palliative Care”

Efforts to build care and payment models are hitting a wall due to the lack of a standardized definition of palliative care services, an article in *Hospice News* reports. [FN180]

Interest in palliative care has been growing among hospices and other health care providers, payers, and policymakers, due to the substantial savings that can be realized in overall health care costs. Studies have found that direct hospital costs can be cut by $3,000 to $4,800 per patient [FN181] and that home-based palliative care could reduce societal health care costs by $103 billion within the next 20 years. [FN182]

Patients and families who are facing serious illness need palliative care, and providers need sustainable payment and clinical models. The lack of a definition can have serious business implications for hospices, who are increasingly diversifying their services to include palliative care but struggle to make their programs profitable or even sustainable. Patients and families not yet facing end-of-life may be put off from choosing palliative care due to misplaced fears that they would have to end curative treatment.

A number of definitions have been adopted by various organizations. Some consider palliative care to be transitional care that takes place when curative treatment is no longer effective, but the patient has not reached the point where they are are hospice eligible. Others recognize that patients can benefit from this care at any point in the course of their illness without interrupting other treatments, particularly when it comes to serious or chronic illness.

D. COVID-19 Patients

In the midst of the growing COVID-19 pandemic, palliative care becomes a pressing need for patients for whom mechanical ventilation is not suitable. Emergency-style palliative care is necessary to meet the needs of patients who won't benefit from a ventilator, say researchers in Switzerland. [FN183] The investigators based their recommendations on the experience of those caring for severely ill patients in a Swiss hospital bordering Italy, where treatment depends on workers inexperienced in palliative care, and resources scarce. Hence, palliative care assessment and treatment plans need to be clear and simple to implement, and decision-making done rapidly as patients deteriorate quickly.

Most patients with COVID-19 need some palliative care due to the large symptom burden and the need for clear and open communication with patients and their families, wrote Professor Nancy Preston, one of the researchers. A conservative approach to treatment is ideal, one that provides maximum support for physical, emotional, and spiritual needs. The authors recommend an initial assessment to identify patients who are stable, unstable, or at the end of life using the early warning parameters for COVID-19. Palliative care management is then formulated with the help of an assessment tool focusing on key symptoms, assessing dyspnoea, distress, and discomfort.

The researchers concluded that during the COVID-19 pandemic palliative care needs to adapt to an emergency style of care as patients can deteriorate rapidly and require quick decisions and clear treatment plans. These need to be easily followed up by generalist staff members caring for these patients. Furthermore, palliative care should be at the forefront to help make the best decisions, give care to families, and offer spiritual support.

E. Music Therapy

The benefits of music therapy in palliative care have become increasingly recognized by health care professionals in North America, since end-of-life treatment is designed to meet the psychosocial, physical, and spiritual needs of patients. A music therapy professor in the Concordia University Department of Creative Arts Therapies, Sandi Curtis, has published a new study on the topic in the journal Music and Medicine. Her findings are based on a collaboration of music therapy students, professional symphony orchestra musicians and a hospital palliative care ward. “Our study showed how music therapy was effective in enhancing pain relief, comfort, relaxation, mood, confidence, resilience, life quality and well-being in patients,” she said. Curtis, who is vice-president elect of the American Music Therapy Association, divided undergraduates and musicians into pairs supervised by an accredited music therapist. The 371 participants were male and female palliative care patients between 18 and 101 years old, all patients who had a terminal illness and most with a diagnosis of cancer. Participants were seen for a single music therapy session, lasting from 15 to 60 minutes, designed to address four areas: pain relief, relaxation, mood, and quality of life. [FN184]

Further, a recent study found that “an evidence-based protocol known as individualized music (IM) offers a non-pharmacological intervention to reduce agitation.” This project, using a one-group pre-test/post-test design, was implemented by training a self-selected sample of 24 hospice professionals to use the IM protocol with dementia patients. The effectiveness of the training on increasing the participants' knowledge of and confidence in using IM was explored. Paired t-tests were employed to analyze the data and the results of the analysis were encouraging, suggesting that it is feasible to educate multidisciplinary hospice staff in implementing the IM protocol,”

wrote M. Gallagher and colleagues. The researchers concluded that there is potential for using IM in the palliative treatment of persons with advanced dementia. The study was published in International Journal of Palliative Nursing. [FN185]

F. “Palliative Care” Triggers Negative Feelings, Study Finds

The term “palliative care” is perceived negatively by cancer patients in a study conducted by researchers at the Princess Margaret Cancer Center in Toronto. [FN186] The researchers analyzed interviews with 48 patients who had advanced cancer and an estimated survival of between 6 and 24 months. Half the patients received early palliative care in an outpatient clinic along with standard cancer care, while the other half received standard cancer care only. Quality of life improved for those who received early palliative care, the study found. At first, “both groups perceived palliative care as synonymous with death; as care at the end of life in a setting where they would die, and in general as a frightening, anxiety-provoking thing they wanted to avoid,” said Dr. Camilla Zimmermann, head of palliative care for the hospital and the University Health Network. But that perception changed among those in the palliative care group, the researchers found. She feels that palliative care has a “branding issue.” “Patients told us if palliative care were called something else, they wouldn't feel so stigmatized.” The study was published April 18, 2016, in the *Canadian Medical Association Journal.*

G. Telehealth Care for Rural Communities: Study

Studies have found that African-Americans living in rural areas are more likely to receive medically ineffective, poor quality care than are Caucasians, according to researchers at the University of Alabama at Birmingham. [FN187] To provide adequate palliative care, the researchers will provide a culturally based palliative care program provided through telehealth in three rural hospitals in the Southeast, and compare that to patients receiving regular care, to see if it helps reduce suffering for patients, increases patient and family quality of life, and reduces the burden of care for caregivers.

Researchers will study 352 hospitalized African-American and white older adults with life-limiting illnesses in three rural, community hospitals in Aiken, South Carolina, Alexander City, Alabama, and Picayune, Mississippi. None of the hospitals have palliative care resources or palliative team members. The care via telehealth will be provided by three different palliative care physicians, including Rodney Tucker, M.D., director of the Center for Palliative and Supportive Care at UAB. The physicians will not be the only ones involved in this process. The researchers will take a team approach to care, including a community advisory group, the hospitalist from each hospital and the patient's on-site care providers.

According to Ronit Elk, Ph.D., the study's co-principal investigator and associate director of the Southeast Institute for Innovation in Palliative and Supportive Care at UAB, even when palliative and hospice services are available, numerous studies have shown that African-Americans underutilize it. The reasons for this include a lack of exposure to hospice and palliative care and a different cultural perspective when it comes to end-of-life care and support.

H. Recent Legislative Activity

Federal

2019 CONG US S 829, introduced March 14, 2019, the “Removing Barriers to Person- and Family-Centered Care Act of 2019” would award cooperative agreements under title XI of the Social Security Act to improve palliative and respite care for individuals with advanced illnesses.

Alaska

2019 AK H.B. 1453 (NS), engrossed February 20, 2019, would create the Perinatal Palliative Care Information Act.

Hawaii

• 2019 HI H.B. 722 (NS), amended/substituted February 14, 2019, would establish the culturally competent palliative care pilot program to promote palliative care, gather health care utilization data, and conduct bidding for at least two pilot programs for home- or community-based palliative care, one of which must be located in a county with less than two hundred thousand residents. The bill would also establish an advisory group to oversee implementation of the pilot program.

• 2019 HI H.B. 1447 (NS), introduced February 6, 2019, would require the Department of Health to establish a culturally competent Palliative Care Pilot Program to promote public education on palliative care and establish home- or community-based palliative care projects.

• 2019 HI H.B. 1638 (NS), introduced January 15, 2020, would require hospitals to provide patients or their designated caregivers with information on hospice and palliative care, if deemed relevant, upon discharge.

• 2019 HI S.B. 582 (NS), introduced January 18, 2019, would appropriate funds as a grant to Hospice of HawaII for capacity building for the community-based palliative care program and as a grant to Kauai Hospice Inc., for the community-based palliative care program.

• 2019 HI S.B. 804 (NS), amended/substituted April 26, 2019, would establish the culturally competent palliative care pilot program within the Department of Health to promote palliative care, gather health care utilization data, and conduct bidding for at least two pilot programs for home- or community-based palliative care, one of which must be located in a county with less than two hundred thousand residents; require reports to the legislature; establish an advisory group to oversee implementation of the pilot program.

Indiana

2020 IN H.B. 1199 (NS), adopted March 14, 2020, defines the terms ‘community based palliative care’ and ‘palliative care’; provides that a hospice provider may provide community based palliative care to a patient who is not eligible for hospice care if the hospice provider: (1) meets certain licensing requirements; and (2) is certified in community based palliative care by an organization approved the state department of health.

Louisiana

• 2020 LA H.B. 455 (NS), engrossed May 15, 2020, would authorize recommendation of medical marijuana by physicians for patients in hospice or palliative care.

• 2020 LA S.B. 483 (NS), introduced March 31, 2020, relative to the licensure of hospice providers, provides for the recommendation by the Palliative Care Interdisciplinary Advisory Council, approval by CMS, minimum standards, rulemaking, and related matters.

Minnesota

2019 MN H.F. 940 (NS), introduced February 11, 2019, and 2019 MN S.F. 1370 (NS), introduced February 18, 2019, would appropriate funds for the Palliative Care Advisory Council for FY 2021.

Mississippi

2020 MS H.B. 1520 (NS), adopted June 25, 2020, allows hospice medical directors to prescribe controlled substances for pain for terminally ill patients without an in-person visit.

New Hampshire

2019 NH H.B. 291 (NS), introduced January 2, 2019, would establish a committee to study certain findings regarding palliative care and associated quality of life, and other initiatives regarding end-of-life care.

New Jersey

• 2020 NJ A.C.R. 53 (NS), introduced January 14, 2020, would urge Congress to pass the ‘Palliative Care and Hospice Education and Training Act’ and fund initiatives to expand palliative care.

• 2020 NJ A.B. 1072 (NS), introduced January 14, 2020, would establish the Working Group on End-of-Life Care and Palliative Care in the Department of Health.

• 2020 NJ S.B. 1816 (NS), introduced on February 24, 2020, would establish the Working Group on End-of-Life Care and Palliative Care in DOH.

New York

• 2019 NY A.B. 608 (NS), introduced January 9, 2019, would require health care professional undergraduate, graduate and continuing education in chronic pain management and treatment.

• 2019 NY A.B. 1078 (NS), adopted November 20, 2019, conforming the definition of palliative care throughout the public health law.

Tennessee

2019 TN S.B. 1697 (NS), adopted March 19, 2020, extends the state palliative care and quality of life council to June 30, 2027.

West Virginia

2020 WV S.B. 748 (NS), adopted March 25, 2020, increasing awareness of palliative care services.

Wisconsin

• 2019 WI A.B. 242 (NS), introduced May 24, 2019, establishing a Palliative Care Council within the Department of Health Services. Under the bill the DHS is required to establish a statewide palliative care consumer and professional information and education program and must make available on its Internet site information and resources regarding palliative care. The bill requires the council to consult with and advise DHS on matters related to the establishment, maintenance, operation, and outcome evaluation of the program established by DHS. The council must also consult with and advise DHS regarding 1) the impact palliative care has on families and the experiences of families that have used or had a family member use palliative care services; 2) establishing a system for identifying patients or residents who could benefit from palliative care and determining how to provide information about and facilitate access to appropriate palliative care services for patients or residents with serious illnesses; and 3) any other issues relating to palliative care arising through meetings or discussions, as the council determines appropriate, but not including physician-assisted suicide.

• 2019 WI S.B. 225 (NS), introduced May 23, 2019, establishing a Palliative Care Council.

VII. AID IN DYING

A. Adoption by States and the District of Columbia

To date, nine states and the District of Columbia have legalized physician-assisted suicide. [FN188] Eight states (**California**, **Colorado**, **Hawaii**, **Maine**, **New Jersey**, **Oregon**, **Vermont**, and **Washington**) and the **District of Columbia** legalized physician-assisted suicide through legislation. Montana **has legal physician-assisted suicide through a court ruling.**

Oregon was the first to legalize assisted suicide, in 1994; an injunction delayed implementation of its Death with Dignity Act [FN189] until October 1997. It remained the only state to have enacted such legislation until Nov. 4, 2008 when **Washington** voters passed Initiative 1000, a ballot measure allowing for physician-assisted suicide. [FN190] Like Oregon's Death with Dignity Act, it allows terminally ill patients to request lethal prescription medications from their physicians. Under the Oregon act, patients must express a desire for suicide assistance in writing, and two witnesses must attest to the request. In addition to the written note, patients must voice their requests aloud to their physicians. The Oregon law specifically prohibits “lethal injection, mercy killing, or active euthanasia,” but it allows mentally competent adults who declare their intentions in writing and who have been diagnosed as terminally ill to take a doctor-prescribed lethal drug themselves, orally, after a waiting period.

In **Washington**, provisions of the newly approved initiative require that two doctors must declare that a patient requesting such a prescription has a terminal illness and is expected to die within six months. The state's 2008 measure was exercised for the first time when Linda Fleming, 66, of Sequim, Washington, suffering from stage 4 pancreatic cancer, chose to end her life with prescribed medication now allowed by the state's assisted suicide law, *The New York Times* reported. [FN191]

The Washington State Department of Health is required, under the Act, to collect information and make available to the public an annual statistical report. [FN192] Use of the state's Death with Dignity law grew slightly in the law's second year, with at least 51 terminally ill patients dying from lethal doses of legally prescribed medication, compared to 36 in 2009. From 2009 to 2015, the number of patients who have died from ingesting the medication has gradually increased. In June 2016, the department reports that 213 people requested and received lethal doses of medication in 2015, written by 142 different physicians and dispensed by 49 different pharmacists. Of the 213 people who received lethal doses of prescription medication, 202 are known to have died; 166 died from ingesting the medication and 24 died for other reasons. Those who died were between the ages of 20 and 97 years old. Most had cancer. According to prescribing physicians, many of the patients who received medication expressed concern about loss of autonomy as a reason for requesting a prescription. [FN193]

While serving as U.S. Attorney General, John Ashcroft worked to overturn Oregon's assisted suicide law. During the past decade, the Supreme Court has ruled on two assisted suicide cases and upheld the constitutionality of the Oregon law. In 2006, the Supreme Court again ruled in favor of Oregon in *Gonzales v. Oregon.* [FN194]

Since Oregon originally legalized assisted suicide, many lawmakers in other states have sought to criminalize the practice. Opponents claim it disrespects human life and presents many public policy implications. They also fear the enormous potential for abuse and contend that it violates a doctor's Hippocratic Oath to heal those who are ill. In addition, some argue that legalizing assisted suicide could grant too much power to doctors to “play God” or encourage medical staff to avoid costly, heroic measures to save critically ill patients.

Proponents of legalized assisted suicide argue that individuals with terminal illnesses should have the right to choose a peaceful passing rather than suffering through the final months of terminal disease. They emphasize that planning for death in advance can guarantee family members an opportunity to say goodbye to ailing loved ones. Additionally, those in favor of the practice argue that physician-assisted suicide reduces the cost of providing end-of-life care to terminal patients who would prefer not to receive it. They claim that reasonable laws can be constructed to prevent abuse while still protecting the value of human life.

In the first decade since **Oregon** passed its controversial law, 541 Oregonians received prescriptions for a lethal dose of medication. To date, 341 have died after ingesting a lethal dose. [FN195] Partly due to the raised awareness about terminal illness brought about by the controversial Oregon law, palliative and hospice care have increased markedly in Oregon, and the state ranks among the best in the nation in end-of-life care.

However, a 2010 survey in the Hastings Center Report found that many hospices in Oregon did not participate in requests by patients for physician-assistance in dying. The survey compiled the responses from 55 hospice program in Oregon (86% of the total number of hospices in Oregon). The report found that hospices' “role is largely confined to providing information about the law in a neutral manner . . . . Patients must then work on their own to find physicians who are willing to help them die.” Of the 55 programs, 52% either did not participate in the law at all, or had very limited participation. In all situations, staff members are forbidden from assisting patients in obtaining or taking medications that will end the patient's life. The study found both legal and moral reasons for the lack of assistance being offered to patients. [FN196]

On October 5, 2015, **California** approved 2015 CA S.B. 128 (NS), the “End of Life Option Act,” authorizing an adult who meets certain qualifications and who has been determined by his or her attending physician to be suffering from a terminal illness, as defined, to make a request for medication prescribed pursuant to these provisions for the purpose of ending his or her life. The measure establishes the procedures for making these requests. It also establishes the forms to request aid-in-dying medication and under specified circumstances an interpreter declaration to be signed subject to penalty of perjury, thereby creating a crime and imposing state-mandated local program.

S.B. 128 provides immunity from civil or criminal liability or professional disciplinary action for participating in good faith compliance with the act and provides that participation in activities authorized pursuant to this bill shall be voluntary. The measure also makes it a felony to knowingly alter or forge a request for medication to end an individual's life without his or her authorization or to conceal or destroy a rescission of a request for medication, if it is done with the intent or effect of causing the individual's death. It also makes it a felony to knowingly coerce or exert undue influence on an individual to request medication for the purpose of ending his or her life or to destroy a rescission of a request. By creating a new crime, the bill imposes a state-mandated local program; provides that nothing in its provisions be construed to authorize ending a patient's life by lethal injection, mercy killing, or active euthanasia; and provides that action taken in accordance with the act shall not constitute, among others, suicide or homicide.

After it passed the California Senate 23-13 on June 4 and the state Assembly 43-34 on Sept. 9, Governor Jerry Brown signed it into law on Oct. 5, 2015, despite intense opposition from some religious and disability rights groups. [FN197] In a rare statement accompanying the signing notice, Brown, a former Roman Catholic seminarian, said he closely considered arguments on both sides of the controversial measure, which makes California only the fifth U.S. state to legalize assisted suicide for terminally ill patients.

The law, which took effect Jan. 1, 2016, makes it a felony to pressure anyone into requesting or taking assisted suicide drugs. Advocates for physician-assisted suicide have tried for decades to persuade California to legalize the practice as a way to help end-stage cancer and other patients to die with less pain and suffering, failing six times in the legislature or the ballot box before finally winning passage last month.

Valeant Pharmaceuticals, the drugmaker that acquired the rights to Seconal, doubled the cost, from $1,500 to more than $3,000 ? and up to $5,000 following passage of California's right-to-die/death with dignity legislation last fall. Seconal is the trade name of secobarbital sodium, the most commonly prescribed drug for aid-in-dying patients. The price increase came on top of previous retail price increases for the nearly 90-year-old sedative that once sold for $150 for a lethal 10-gram dose. California's Medicaid program plans to cover the drug although health insurance often doesn't pay for aid-in-dying drugs, and they are not covered under Medicare. In Washington, the drugs aren't covered under the state Medicaid plan or by several Catholic health systems that prohibit doctor-aided death based on religious objections.

Washington State decided to seek an alternative to the high-priced Seconal and turned to a compounding pharmacist. The result was a less-expensive mix of three medications: phenobarbital, chloral hydrate, and morphine sulfate, all in powdered form to be mixed with water, alcohol, applesauce, or juice. The new mix of medications sells for about $500. Now doctors in Oregon have adopted the drug mix, too, as a way to ensure that cost doesn't prevent terminally ill patients from making the choice they want under the state's right-to-die law. California officials are considering it as well.

As of December 31, 2016, 111 California residents died with the help of doctor-prescribed drugs under the state's new aid-in-dying law, according to a first-of-its-kind report released Tuesday. Nearly 200 received the drugs under the law, the report said. The End of Life Option Act went into effect on June 9, 2016, ending years of debate over whether the state should allow a mentally competent adult, diagnosed with less than six months to live, to end their life with a lethal drug prescription from their doctor. The law also mandated publication of an annual report by the California Department of Public Health that provides specific details about anyone who requested and may have ingested the drugs. Released on June 27, 2017, the report analyzes statistics from June 9 through December 31, 2016, based on information contained in physicians' forms and California death certificates.

Highlights of the report include:

• Of the 191 individuals who were prescribed the drugs, 111 (or 58.1 percent), were reported to have died following ingestion of the drugs; and 21 individuals (11.0 percent) died without ingestion of the drugs. The outcome of the remaining 59 individuals, or 30.9 percent, who had been prescribed aid-in-dying drugs, was undetermined, as there had been no outcome reported as of Dec. 31, 2016.

• Nearly 60 percent were suffering from cancer; 18 percent had been diagnosed with a neuromuscular disorder like ALS or Parkinson's disease; 9 percent from heart disease; 7% percent from respiratory diseases.

• The median age of people who used the new law was 73; 42 percent were aged 80 and over.

• The decedents were 89.5 percent white, 6 percent Asian, 3 percent black, and 3 percent Hispanic; 54.1 percent were female.

• 83.8 percent were receiving hospice and/or palliative care, and 72.1 percent had at least some level of college education

On May 15, 2018, a Riverside County Superior Court judge overturned California's physician-assisted suicide law, which allows terminally ill patients to request lethal medications from their doctors. Judge Daniel A. Ottalia said that the California Legislature violated the law by passing the End of Life Option Act during a special session dedicated to healthcare issues. The state attorney general has five days to file an appeal to keep the law in place.

An attorney representing Compassion and Choices, which advocated for the law, said he believes the passage of the law was constitutional because aid in dying is a healthcare issue. Alexandra Snyder, head of the Life Legal Defense Foundation, one of the groups that filed the lawsuit said ‘We're very happy with the decision today. We will now wait and see what the attorney general does.’

In a statement sent to the *Los Angeles Times*, California Attorney General Xavier Becerra said: “We strongly disagree with this ruling and the state is seeking expedited review in the court of Appeal.” [FN198]

Colorado voters on November 8, 2016 approved Proposition 106 to allow a terminally ill adult to take a prescribed drug to cause his or her death. The measure, called “Medical Aid in Dying,” restricts the drugs to those who are at least 18, have a terminal illness with less than six months to live, and are able to self-administer the medications. Two physicians would have to sign off on the terminal diagnosis, and the patient would have to be mentally competent. Colorado became the sixth state in the U.S. (after **Washington**, **Vermont**, **Oregon**, **California**, and **Montana**) to allow patients to take drugs to end their lives.

On December 20, 2016, **District of Columbia** mayor Muriel Bowser signed the Death with Dignity Act of 2015, bringing the District one step closer to making assisted dying available to terminally ill patients. City council approved the bill on November 15, 2016, by an 11 to 2 margin. The measure would allow terminally ill patients 18 years or older and with six months or less to live the ability to obtain life-ending, physician-prescribed medicine. Two witnesses have to verify that the patient's decision is voluntary, and the medication must be self-administered. Since Congress failed to disapprove the Act with a joint resolution, the District became the seventh jurisdiction with an assisted dying statute. [FN199]

A House subcommittee has added a policy rider to a government appropriations bill (2017 US HR 6147) that would repeal the medical aid in dying bill in the District of Columbia. The rider was not approved in the Senate subcommittee version of the bill. D.C. Congresswoman Eleanor Holmes Norton authored an amendment to eliminate the rider, but the House Rules Committee refused to allow debate on it. The D.C. City Council passed the Death with Dignity Act with an overwhelming majority in 2016, with the support of most D.C. residents.

After decades of debate, **Hawaii** has become the sixth state, along with the District of Columbia, to enact legislation (2017 HI H.B. 2739 (NS)) allowing a mentally competent adult resident who has a terminal illness to voluntarily request and receive a prescription medication to die in a peaceful, humane, and dignified manner.

Dubbed the “Our Care, Our Choice Act,” the legislation contains the following safeguards, to protect patients and their loved ones from any potential abuse:

• Confirmation by two health care providers of the patient's diagnoses, prognosis, and medical decision-making capacity, and the voluntariness of the patient's request;

• Determination by a counselor that the patient is capable, and does not appear to be suffering from undertreatment or nontreatment of depression or other conditions which may interfere with the patient's ability to make an informed decision;

• Two oral requests from the patient, separated by not less than twenty days; one signed written request that is witnessed by two people, one of whom must be unrelated to the patient; and one signed final attestation;

• An additional waiting period between the written request and the writing of the prescription; and

• The creation of strict criminal penalties for any person who tampers with a person's request for a prescription pursuant to this Act, or coerces a person with a terminal illness to request a prescription.

In addition, the patient at all times shall retain the right to rescind the request for medication and be under no obligation to fill the prescription or use the medication.

New Jersey adopted the Medical Aid in Dying for the Terminally Ill Act (2018 NJ A.B. 1504 (NS)) on April 12, 2019. One week after the law originally took effect, a physician who opposes the law on religious grounds filed suit in Superior Court to enjoin the law. Superior Court Judge Paul Innes in Mercer County granted a temporary restraining order on August 14, preventing doctors from writing prescriptions. The temporary restraining order had suspended the Act because although the state statute contains regulations, there are no administrative rules yet. On August 27, a state appellate court ruled that agencies and regulatory boards did not need to establish rules before the law could go into effect, and overturned the restraining order. Subsequently, the Supreme Court of New Jersey denied the plaintiff's emergency application to reverse the appellate court's ruling.

In June 2019, **Maine** became the eighth state to legalize medically assisted suicide. Governor Janet Mills signed the Maine Death with Dignity Act (ME H.P. 948 (NS)) on June 12, 2019, which lays out the steps a patient and physician must take before a person can legally end their life. The law requires the patient to undergo two waiting periods and one written and two oral requests and obtain opinions from at least two physicians that a medically assisted suicide is appropriate. The patient must be 18 years of age or older, meet certain qualifications, has been determined by the person's attending physician to be suffering from a terminal disease to make a request for medication to end the person's life.

The bill criminalizes coercing a patient into requesting life-ending medication and falsifying a request for the procedure.

B. Public Support

A Gallup poll in 2015 found that 68% of Americans feel doctors should be legally allowed to assist terminally ill patients to commit suicide. This a marked increase of 10% over the finding in 2014 and, support for euthanasia has risen nearly 20 percentage points over the last two years and stands at the highest level in over a decade. Gallup reports that most of the increased support came from 18- to 34-year-olds. Unlike earlier polls, use of the word “suicide” did not appear to temper support of doctor-assisted suicide. Further, a majority of Americans (56%) now say that doctor-assisted suicide is “morally acceptable, an increase of seven points since 2001. [FN200]

C. Faith-based Hospitals Oppose Aid-in-Dying Laws

When Colorado veteran geriatrician Dr. Barbara Morris went to court to fight for the right of her patient to use the state's medical aid-in-dying law, her employer, Christian-run Centura Health Corp. fired her, citing religious doctrine that describes “assisted suicide” as “intrinsically evil.” [FN201] According to Definitive Healthcare, 5 of the top 10 hospital systems by net patient revenue are associated with the Roman Catholic Church, including hospitals that did not previously have any religious affiliation. [FN202] At the same time, there are 10 jurisdictions in the U.S. where aid-in-dying has been approved, and public support for the option is increasing.

Centura claims that Morris violated the firm's governing rules, the Ethical and Religious Directives for Catholic Health Care Services. The directives state that Catholic health care providers “may never condone or participate in euthanasia or assisted suicide in any way.” According to a spokeswoman, Centura believes that the freedom of religion doctrine “at the heart of the First Amendment to the U.S. Constitution supports our policies as a Christian health-care ministry.” According to the *KHN* article, the argument based on the First Amendment has gained support recently in conservative circles. Support for provider resistance in the Trump Administration is evidenced by adoption in May 2019 of the so-called “conscience rule” that strengthens the rights of hospitals and health workers to refuse to participate in patient care based on religious or moral grounds. [FN203]

D. Opposition by Justice Gorsuch

In a book published in 2006, recently confirmed Supreme Court Justice Neil Gorsuch examines the ethical, legal, and philosophical issues surrounding assisted suicide and euthanasia and stands firmly opposed to it. [FN204] Gorsuch, President Trump's nominee for Associate Justice of the U.S. Supreme Court, was confirmed on April 6, 2017. In the book, Gorsuch argues against death with dignity laws, which currently exist in eight states and the District of Columbia. His reasons stem from the belief in the “inviolability of human life.” As he writes in the book, “All human beings are intrinsically valuable, and the intentional taking of human life by private persons is always wrong.” At the confirmation hearing, when questioned by Sen. Diane Feinstein on assisted suicide, he responded that “the position I took on that in the book was, anything necessary to alleviate pain would be appropriate and acceptable, even if it caused death?not intentionally but knowingly. I drew a line between intent and knowingly.” [FN205]

E. When Palliative Sedation at End of Life is Appropriate

According to a new review article in the October 2010 issue of Mayo Clinic Proceedings, “palliative sedation at the end of life is ethically sound and has an important place on the continuum of appropriate palliative care.” The article states that the difference between palliative sedation and euthanasia/physician-assisted suicide is the intent and the outcome. According to the physician reviewers, “the intent of palliative sedation is to relieve unremitting and intractable suffering, while the intent of euthanasia and physician-assisted suicide is to end the patient's life.” [FN206]

F. Veterans

Although California voters approved a law two years ago that allows terminally ill people to take lethal drugs to end their lives, controversy is growing over a newer rule that effectively bans that option in the state's eight veterans homes. According to *Kaiser Health News*, proponents of medical aid-in-dying and residents of the Veterans Home of California-Yountville (the largest in the nation) are protesting a regulation passed last year by the California Department of Veterans Affairs (“CalVet”) that requires that anyone living in the facilities be discharged if they intend to use the law.

That's a position shared three other states?Oregon, Colorado, and Vermont?that prohibit use of lethal medication in state-run veterans homes. A CalVet official said the agency adopted the rule to avoid violating a federal statute (42 U.S.C. ?14402) that prohibits using U.S. government resources for physician-assisted death. Otherwise, the agency would jeopardize nearly $68 million in federal funds that helps run the facilities, said June Iljana, CalVet's deputy secretary of communications. [FN207]

G. Recent Legislative Activity

Federal

2019 CONG US HCON 79, introduced December 12, 2019, expressing the sense of the Congress that assisted suicide puts everyone, including those most vulnerable, at risk of deadly harm.

Alaska

2019 AK H.B. 1536 (NS), introduced February 20, 2019, would create the Compassionate Care End-Of-Life Option Act; exempt prescribing or dispensing of a medication for self-administration by a patient under the Act from the definition of “physician-assisted suicide”; modify limitation of liability of life insurance policies.

Arizona

• 2020 AZ H.B. 2582 (NS), filed January 17, 2020, would allow an adult resident of the state who is capable, who the attending physician and consulting physician have determined is suffering from a terminal illness and who has voluntarily expressed a wish to die may make a written request for a prescription for medication to end his or her life.

• 2020 AZ S.B. 1497 (NS), introduced February 3, 2020, the ‘Death with Dignity Act of 2020,’ would provide for person suffering from a terminal condition, of sound mind, to request and receive medication to end the patient's life.

Delaware

2019 DE H.B. 140 (NS), introduced May 2, 2019, would recognize and provide that a terminally ill adult individual who has decision-making capacity has the right to request and self-administer medication to end their life in a humane and dignified manner; that an individual should not be coerced, pressured, or otherwise compelled to take medication to end their life and the decision to self-administer medication to end life must be made voluntarily by a terminally ill adult individual with decision-making capacity, not by a guardian or other surrogate health-care decision maker or by the individual in an advance health-care directive; that health-care providers should not be subject to civil or criminal liability or professional discipline for honoring a request from a terminally ill adult individual for medication to end their life in a humane and dignified manner that is made in compliance with the requirements of this chapter; and that the self-administration of medication to end life in a humane and dignified manner by a terminally ill adult should not impact life insurance or annuity policies.

Florida

2020 FL S.B. 1800 (NS), introduced January 22, 2020, would create the “Death with Dignity Act” providing criteria for qualified patients; requiring qualified patients to make oral and written requests for medication; requiring waiting periods before such requests may be made and such medication may be prescribed; specifying requirements for attending physicians; authorizing the attending physician to sign the qualified patient's death certificate, etc.

Georgia

2019 GA S.B. 291 (NS), introduced January 15, 2020, the ‘Georgia Death with Dignity Act,’ would create provisions for physician-assisted end-of-life options for terminally ill individuals.

Hawaii

2019 HI S.B. 3047 (NS), introduced January 23, 2020, would allow an advance directive to be a valid written request for a prescription to be self-administered for the purpose of ending an adult's life; would include advanced practice registered nurses under the definition of ‘attending provider’; would allow an attending provider to waive the counseling referral requirement; would allow an attending provider to perform duties through telehealth, under certain conditions; and would require health insurance policies and contracts issued after December 31, 2020, to provide coverage for services related to ending a patient's life.

Iowa

• 2019 IA S.F. 175 (NS), introduced February 4, 2019, and 2019 IA H.F. 374 (NS), introduced February 13, 2019, would create the Iowa End-of-Life Options Act and providing penalties.

• 2019 IA S.F. 2156 (NS), introduced February 5, 2020, creating the Our Care, Our Options Act, would allow a patient who is mentally capable, a resident of this state, and has been certified by a health care provider to be terminally ill, to request medication that the patient may self-administer to end the patient's life.

Kansas

2019 KS H.B. 2089 (NS), introduced January 28, 2019, would enact the Kansas Death with Dignity Act that would allow an adult who has been determined by such adult's attending physician and consulting physician to be suffering from a terminal disease, and who has voluntarily expressed such adult's wish to die, to make a written request for medication for the purpose of ending such adult's life in a humane and dignified manner.

Kentucky

2020 KY H.B. 224 (NS), introduced January 9, 2020, the Kentucky Death with Dignity Act, would establish a qualified terminally ill patient's right to voluntarily request medication to self-administer to cause death; require conditions for making the request; permit the patient to rescind the request at any time; permit an attending physician to provide medication; establish requirements for the attending physician to inform patients and document the request; require disposal of unused medications; establish residency requirements for qualified patients; require reports by the Cabinet for Health and Family Services; establish provisions for contracts, insurance policies, and beneficiaries; prohibit applicability of provisions to ending a patient's life by lethal injection, mercy killing, or active euthanasia; state that a health care provider is not required to provide medication to a qualified patient; permit health care providers to prohibit a person or entities from participating in a qualified patient's request during or on the premises of employment; prohibit reporting a health care provider to a licensing board for participating in a qualified patient's request; state that actions under this Act do not authorize lethal injection, mercy killing or active euthanasia; state that actions under this Act do not constitute suicide or homicide; create a form for a qualified patient to make a request; create a form for an interpreter for a qualified patient making a request; establish provisions for insurance policies and beneficiaries of qualified patients; create an affirmative defense to a charge of murder and manslaughter in the first degree.

Maine

2019 ME H.R. 1469 (NS), adopted March 18, 2020, final adoption of Death with Dignity Act reporting rule.

Massachusetts

2019 MA H.B. 4782 (NS), introduced June 15, 2020, and 2019 MA S.B. 2745 (NS), introduced June 8, 2020, relative to end-of-life options.

Minnesota

2019 MN S.F. 2487 (NS), introduced March 14, 2019, 2019 MN S.F. 2286 (NS), introduced March 11, 2019, and 2019 MN H.F. 2152 (NS), introduced March 7, 2019, would establish an end-of-life option for terminally ill adults, and impose criminal penalties.

New Hampshire

2019 NH H.B. 1659 (NS), introduced January 8, 2020, would allow a mentally competent person who is 18 years of age or older and who has been diagnosed as having a terminal disease by the patient's attending physician and a consulting physician, to request a prescription for medication which will enable the patient to control the time, place, and manner of such patients death. Under this bill, the request is witnessed and signed in essentially the same manner as an advance directive. The bill also requires the division of public health services, department of health and human services, to collect certain information and compile a statistical analysis of such information.

New York

• 2019 NY A.B. 30 (NS), introduced January 9, 2019, would require the commissioner of health to conduct a study of the issues, implications, practices, licensure requirements and other topics relating to medical aid in dying.

• 2019 NY A.B. 2694 (NS), introduced January 25, 2019, the Medical Aid in Dying Act, would provide for a terminally ill patient's request for and use of medication for medical aid in dying.

North Carolina

2019 NC H.B. 879 (NS), introduced April 22, 2019, establishing an end-of-life option to allow qualified patients diagnosed with a terminal disease to end life in a humane and dignified manner.

Pennsylvania

• 2019 PA H.B. 2033 (NS), introduced November 14, 2019, would provide for compassionate assisted dignified death by allowing a qualified patient to make a request for end-of-life medication for the purpose of ending his or her life in a compassionate, humane, and dignified manner.

• 2019 PA S.B. 1225 (NS), introduced July 10, 2020, providing for end of life options, for duties of attending physicians and consulting physicians, and for insurance or annuity policies; imposing duties on the Department of Health; providing for immunities; and imposing penalties.

Rhode Island

2019 RI S.B. 2265 (NS), introduced on February 4, 2020, would create the Lila Manfield Sapinsley Compassionate Care Act, to provide a legal mechanism whereby a terminally ill patient may choose to end their life using drugs prescribed by a physician.

Virginia

2020 VA H.B. 1649 (NS), introduced January 16, 2020, would allow an adult diagnosed with a terminal condition to request, and an attending health care provider to prescribe, a self-administered controlled substance for the purpose of ending the patient's life in a humane and dignified manner. The bill requires that a patient's request for a self-administered controlled substance to end his life must be given orally on two occasions and in writing, signed by the patient and one witness, and that the patient be given an express opportunity to rescind his request at any time. The bill makes it a Class 2 felony (i) to willfully and deliberately alter, forge, conceal, or destroy a patient's request, or rescission of request, for a self-administered controlled substance to end his life with the intent and effect of causing the patient's death; (ii) to coerce, intimidate, or exert undue influence on a patient to request a self-administered controlled substance for the purpose of ending his life or to destroy the patient's rescission of such request with the intent and effect of causing the patient's death; or (iii) to coerce, intimidate, or exert undue influence on a patient to forgo a self-administered controlled substance for the purpose of ending the patient's life. The bill also grants immunity from civil or criminal liability and professional disciplinary action to any person who complies with the provisions of the bill and allows health care providers to refuse to participate in the provision of a self-administered controlled substance to a patient for the purpose of ending the patient's life.

Washington

• 2019 WA H.B. 2326 (NS), introduced January 13, 2020, would require hospitals to submit their policies regarding end-of-life care and the death with dignity act.

• 2019 WA H.B. 2419 (NS), amended/substituted January 31, 2020, studying barriers to the use of the Washington death with dignity act.

Wisconsin

• 2019 WA H.B. 2419 (NS), enrolled March 10, 2020, relating to studying barriers to the use of the Washington death with dignity act.

• 2019 WI S.B. 499 (NS), introduced October 10, 2019, and 2019 WI A.B. 552 (NS), introduced October 18, 2019, would permit certain individuals to make requests for medication for the purpose of ending their lives; and would provide a penalty for violations.

VIII. “RIGHT TO TRY”

A. U.S. “Right to Try” Laws May Not Help Dying Get Unapproved Drugs

So-called “right to try” laws, intended to expand dying patients' access to experimental treatments, may not work as expected ? and might strip patients of federal safety protections, some experts say. [FN208] The laws, enacted in at least 24 states, have been promoted as a way to help dying patients get hold of medicines and devices that haven't been approved by the U.S. Food and Drug Administration (FDA). But the laws haven't yet helped patients gain access to experimental therapies, Alison Bateman-House, an ethicist at New York University Langone Medical Center, and colleagues argue in an article in Annals of Internal Medicine.

The state laws may also cover access only for terminally ill patients, excluding people with serious or rare diseases with limited treatment options that are not immediately life-threatening, the authors note. And the laws may disrupt the current system for granting so-called “compassionate use” of unproven treatments to dying or seriously ill patients, which includes FDA oversight to track any safety issues, Bateman-House said by email.

Under current federal policy, when terminally ill patients want to use drugs and devices that are too early in their development to be approved by the FDA, their doctors typically ask for the drug or device companies to grant expanded access to the experimental therapies.

If the company agrees, the FDA and a review board where the physician works would also vet the request. Among other things, reviewers might assess whether the patient has exhausted other options and understands the potential risks and benefits of therapies that generally haven't yet been tested in large-scale human trials.

The FDA has not taken a position on right to try legislation, Sarah Peddicord, an FDA spokeswoman, said by email. The FDA approved more than 99 percent of compassionate use applications, also known as expanded access requests, received during the 2010 to 2014 fiscal years, she said. The FDA is required to respond to these requests within 30 days, but often does so much more quickly, she added.

States have approved right to try laws, however, because the current system doesn't move quickly enough for terminally ill patients who seek experimental treatments as a last resort, said Kurt Altman, director of national affairs at the Goldwater Institute, which has drafted model legislation and helped promote the laws.

He doesn't dispute the FDA's 99 percent approval rate for compassionate use requests. Instead, Altman argues that these requests represent only a fraction of the patients who might have benefited from getting experimental treatments.

”What the 99 percent figure does not tell us is how many terminal patients didn't know about expanded access, had a doctor with insufficient time to complete the process, etc.,” Altman said by email.

The application can take doctors more than 100 hours to complete, he said. Though the FDA announced plans to streamline this process so it takes only 45 minutes, Altman said he isn't aware of this being implemented yet.

“Overall, I think right to try is a first step that will lead to reforms that not only speed some FDA processes but also make their processes more transparent and understandable,” Altman said.

B. Recent Legislative Actions

Mississippi

2020 MS S.B. 2830 (NS), adopted June 25, 2020, amends the Right to Try Act to revise definitions to include traumatic injury and adult autologous mesenchymal stem cell.

Pennsylvania

2019 PA S.B. 307 (NS), introduced February 19, 2019, would provide for the use of investigational drugs, biological products, and devices by terminally ill patients under 18 years of age.

IX. ORGAN DONATION AND TRANSPLANTATION

Organ donation takes place when a person allows healthy transplantable organs and tissues to be removed, either after death or while the donor is alive, and transplanted into another person. Common transplantations include: kidneys, heart, liver, pancreas, intestines, lungs, bones, bone marrow, skin, and corneas.

The field of organ donation and transplantation is one of the most regulated areas of health care today. Both state and federal legislation has been put in place to provide the safest and most equitable system for allocation, distribution, and transplantation of donated organs. To address the nation's critical organ donation shortage and improve the organ matching and placement process, the U.S. Congress passed the National Organ Transplant Act in 1984. The act established the Organ Procurement and Transplantation Network (OPTN) to maintain a national registry for organ matching. The Act also called for the network to be operated by a private,

nonprofit organization under federal contract. The United Network for Organ Sharing (UNOS), based in Richmond, Virginia, administers the OPTN under contract with the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS).

On the state level, laws facilitate organ and tissue donation commitments, including revenue sources and funding, legal consent for donation, donation education, and living donor support. A website [FN209] provided by HRSA supplies extensive and detailed information on state legislation.

Recent Legislative Activity

Alabama

• 2020 AL H.B. 58 (NS), introduced February 4, 2020, would prohibit discrimination against an individual from receiving an organ transplant based on the individual having a disability. This bill would also require health care practitioners, hospitals and other health care facilities, and organ transplant centers to provide reasonable accommodations to an individual with a disability in medical need of an anatomical gift or organ transplant.

• 2020 AL S.B. 225 (NS), introduced February 20, 2020, would prohibit discrimination against an individual from receiving an organ transplant based on the individual having a disability. The bill would also require health care practitioners, hospitals and other health care facilities, and organ transplant centers to provide reasonable accommodations to an individual with a disability in medical need of an anatomical gift or organ transplant.

Alaska

2019 AK S.B. 317 (NS), filed February 13, 2019, would prohibit discrimination against individuals with disabilities regarding access to organ transplantation; require covered entities to make reasonable modifications to policies, practices, and procedures; and provide auxiliary aids and services during the organ transplantation process.

Arizona

2020 AZ H.B. 2861 (NS), introduced February 12, 2020, would provide for the presumed consent of residents to making an anatomical gift of certain organs, eyes, or tissues upon their death; opting out.

California

• 2019 CA A.B. 810 (NS), introduced February 20, 2019, would require the State Department of Public Health to convene a working group to evaluate ways to provide organ transplants to uninsured or undocumented residents of the state who are ineligible for organ transplants due to financial hardship. The bill would require the working group to submit its findings and recommendations to the Legislature on or before January 1, 2021, as specified. The bill would require the working group to be comprised of representatives from certain entities, including, among others, community-based immigrant rights and health organizations. The bill would require the working group to evaluate relevant data, including, but not limited to, the number of organ donors who are undocumented residents of the state and the percentage of organ transplant recipients who are medically insured. The bill would repeal these provisions on January 1, 2021.

• 2019 CA S.B. 325 (NS), introduced February 15, 2019, would authorize anatomical gifts to be made to approved nursing schools.

• 2019 CA S.B. 685 (NS), introduced February 22, 2019, would require the Department of Motor Vehicles to notify the registry if a person who has previously requested to be on the Donate Life California Organ and Tissue Donor Registry checks a box indicating that they do not wish to be on the registry; would also make minor changes to the check boxes and would additionally require the back of the application, upon the department's next scheduled revision, to contain a statement informing the applicant of the consequences of their decision.

Connecticut

• 2020 CT H.B. 5255 (NS), introduced February 20, 2020, would (1) prohibit insurance providers from discriminating against any individual solely because such individual is a living organ donor, and (2) provide that such discrimination constitutes a violation of the Connecticut Unfair Insurance Practices Act.

• 2020 CT S.B. 457 (NS), introduced March 10, 2020, prohibiting discrimination against an individual with a disability who is a candidate to receive an anatomical gift.

District of Columbia

2019 DC L.B. 94 (NS), introduced January 22, 2019, would amend the Healthy Schools Act of 2009 to require that District of Columbia Public Schools and Public Charter Schools provide education on the process of making an anatomical gift, including information about the life-saving and life-enhancing effects of organ, eye, and tissue donation to help students become better informed.

Florida

• 2020 FL H.B. 1179 (NS), adopted June 29, 2020, prohibiting certain entities from making determinations or engaging in actions related to organ transplants solely on basis of individual's disability; providing cause of action for injunctive & other relief; prohibiting

insurers, nonprofit health care service plans, and HMOs that provide coverage for organ transplants from denying coverage solely on basis of individual's disability.

• 2020 FL H.B. 1187 (NS), amended/substituted February 6, 2020, would prohibit a health insurance policy from limiting or excluding coverage solely on the basis that the insured is an organ donor; would revise provisions relating to anatomical gifts; prohibit an organ transplantation facility from charging certain persons for specified services; require the AHCA to establish an Organ Transplant Technical Advisory Council; revise duties of the Organ & Tissue Procurement & Transplantation Advisory Board; and provides duties of the AHCA relating to organ donation.

• 2020 FL S.B. 1516 (NS), amended/substituted January 28, 2020, prohibiting a health insurance policy from limiting or excluding coverage solely on the basis that an insured is a living organ donor; revising a written document for making an anatomical gift to include a specified statement relating to the responsibility of payment for fees associated with certain services; revising the responsibilities of a contractor procured by the agency for the purpose of educating and informing the public about anatomical gifts; prohibiting an organ transplantation facility from charging a donor or his or her family member any fee for services relating to the procurement or donation of organs, etc.

• 2020 FL S.B. 1556 (NS), amended/substituted February 11, 2020, prohibiting entities from making certain determinations or engaging in actions related to organ transplants solely on the basis of an individual's disability; specifying an instance where certain entities may consider an individual's disability, with an exception; requiring certain entities to take necessary steps to ensure an individual with a disability is not denied services, with exceptions; prohibiting insurers, nonprofit health care service plans, and health maintenance organizations that provide coverage for organ transplants from denying coverage solely on the basis of an individual's disability under certain circumstances, etc.

Georgia

2019 GA H.B. 842 (NS), amended/substituted on February 28, 2020, Gracie's Law, would prohibit providers from discriminating against potential organ transplant recipients due solely to the physical or mental disability of the potential recipient.

Hawaii

2019 HI H.B. 2340 (NS), adopted September 15, 2020, would clarify prohibited actions related to anatomical gifts and disposition of bodies.

Illinois

• 2019 IL H.B. 2756 (NS), filed February 14, 2019, would amend the Illinois Anatomical Gift Act to provide that the term “decedent” include a deceased individual organism of the species homo sapiens from fertilization until live birth; provide that notwithstanding any other provision of the Act, if the decedent is a fetus upon whom an abortion has been performed, then no part of the decedent's body may be used for any purpose specified in the Act.

• 2019 IL H.B. 5299 (NS), filed February 14, 2020, would amend the Illinois Anatomical Gift Act to provide that an anatomical gift may be made, for the training of search and rescue canines, to a person operating within a State agency, emergency management agency, or local law enforcement agency.

• 2019 IL H.B. 5525 (NS), introduced February 18, 2020, would provide that the Department of Insurance: provide information to the public on the access to insurance for a living organ donor; make any received materials related to live organ donation from a recognized live organ procurement organization available to the public; amend the Illinois Anatomical Gift Act; provide that a person with a physical or mental disability is not required to demonstrate postoperative independent living abilities in order to have access to a transplant if there is evidence that the person will have sufficient, compensatory support and assistance; provide that if the Secretary of State receives materials related to live organ donation from a recognized live organ procurement organization, the Secretary shall make the materials available to the public; provide that the Secretary may seek and accept gifts, grants, or donations from private or public sources.

• 2019 IL S.B. 3419 (NS), introduced February 14, 2020, would create the Non-Transplant Organ Donation Regulation Act; require non-transplant organ donation organizations that acquire or transfer human bodies or human body parts for education, research, or the advancement of medical, dental, or mortuary science to register with the office of the Secretary of State and be licensed by the Department of Public Health; provide requirements for license application, accreditation, renewal, and fees.

Indiana

• 2020 IN H.B. 1087 (NS), introduced January 7, 2020, would provide that an individual may make an anatomical gift to an unspecified individual who is currently on an organ transplant wait list maintained by a hospital located in Indiana; provide that if the anatomical gift cannot be used for an in-state transplant and there is not a contrary instruction, the gift passes to an appropriate organization.

Iowa

• 2019 IA H.F. 2118 (NS), introduced January 23, 2020, relating to protections for certain potential recipients of anatomical gifts.

• 2019 IA H.F. 2561 (NS) adopted June 25, 2020, relating to protections for certain potential recipients of anatomical gifts.

Kansas

2019 S.B. 194 (NS), introduced February 15, 2019, would amend provisions related to the Revised Uniform Anatomical Gift Act.

Louisiana

2020 LA H.B. 615 (NS), engrossed May 22, 2020, would provide that unintentional acts or omissions by organ procurement organizations towards a donor of an anatomical gift is considered medical malpractice.

Maryland

• 2020 MD H.B. 1133 (NS), introduced February 6, 2020, altering the purposes for which certain anatomical gifts may be used; repealing provisions of law that require certain persons to search certain individuals for a document of gift or any other information identifying the individual as a donor, that specify certain procedures to be taken if a document is located, and that concern certain administrative sanctions; requiring a certain procurement organization to make a certain search of certain registries under certain circumstances; authorizing certain examinations of certain medical and dental records to include examination of the death certificates of certain individuals; and generally relating to the Maryland Revised Uniform Anatomical Gift Act.

• 2020 MD S.B. 869 (NS), engrossed March 10, 2020, revisions to Maryland Revised Uniform Anatomical Gift Act; altering the purposes for which certain anatomical gifts may be used; repealing provisions of law that require certain persons to search certain individuals for a document of gift or any other information identifying the individual as a donor, that specify certain procedures to be taken if a document is located, and that concern certain administrative sanctions; requiring a certain procurement organization to make a search of certain registries under certain circumstances.

Louisiana

2020 LA H.B. 615 (NS), adopted June 11, 2020, provides that unintentional acts or omissions by organ procurement organizations towards a donor of an anatomical gift are considered medical malpractice.

Michigan

• 2019 MI H.B. 5484 (NS), introduced February 11, 2020, would allow HIV positive organ donations when the recipient is HIV positive.

• 2019 MI H.B. 6324 (NS), introduced November 10, 2020, would prohibit discrimination against organ transplant recipients based on physical or mental disability.

• 2019 MI S.B. 1201 (NS), introduced October 21, 2020, would prohibit discrimination against organ transplant recipients based on physical or mental disabilities.

Minnesota

• 2019 H.F. 1247 (NS), introduced February 14, 2019, would require an anatomical gift that is an eye or an eye part be passed on to the Lions Gift of Sight at the University of Minnesota.

• 2019 MN H.F. 3078 (NS), introduced February 11, 2020, to ensure that residents in need of organ transplants will not encounter discrimination on the basis of a disability.

• 2019 MN S.F. 301 (NS), introduced January 22, 2019, would require any anatomical gift that is an eye or eye part to be passed to the Lions Gift of Sight at the University of Minnesota.

• 2019 MN S.F. 3035 (NS), introduced February 13, 2020, organ transplant access nondiscrimination public policy establishment and discrimination prohibition.

Mississippi

2020 MS H.B. 414 (NS), engrossed March 4, 2020, would enact Cole's Law to prohibit discrimination against recipients of an anatomical gift or organ transplant

Missouri

• 2020 MO S.B. 551 (NS), adopted July 14, 2020, prohibiting discrimination in insurance against any person based solely on the person's status as a donor.

• 2020 MO S.B. 712 (NS), introduced January 8, 2020, would modify provisions relating to anatomical gifts to persons with disabilities.

• 2020 MO H.B. 1709 (NS), amended/substituted February 17, 2020, relating to long-term care insurance, life insurance, and accident and sickness insurance for living organ donors.

Nebraska

2019 NE L.B. 228 (NS), introduced January 14, 2019, would prohibit certain insurance practices relating to a person's status as a living organ donor.

2019 NH H.B. 1331 (NS), introduced January 8, 2020, would clarify that a person's decision to donate his or her own body, organ, or tissue upon death is not subject to amendment or revocation after such person's death.

New Hampshire

2019 NH H.B. 1331 (NS), amended/substituted March 11, 2020, clarifying that a person's decision to donate his or her own body, organ, or tissue upon death is not subject to amendment or revocation after such person's death.

New Jersey

• 2018 NJ A.B. 1449 (NS), adopted January 21, 2020, provides job security to certain organ and bone marrow donors.

• 2020 NJ A.B. 2217 (NS), introduced January 14, 2020, would provide for opting out of organ and tissue donation.

• 2020 NJ A.B. 2218 (NS), introduced January 14, 2020, would provide that the organ donor designation on a driver's license or identification card remains upon renewal of a license or card under certain circumstances.

• 2020 NJ A.B. 3199 (NS), amended/substituted October 19, 2020, would prohibit discrimination against living organ donors in relation to life, health, and long-term care insurance.

• 2020 NJ A.B. 3558 (NS), introduced on February 25, 2020, would require insurers to provide information about organ donation and allow insurers to limit reimbursement for organ transplant if recipient has not made gift pursuant to Revised Uniform Anatomical Gift Act.

• 2020 NJ S.B. 510 (NS), introduced January 14, 2020, would require insurers to provide information about organ donation and allow insurers to limit reimbursement for organ transplant if recipient has not made the gift pursuant to Revised Uniform Anatomical Gift Act.

• 2020 NJ S.B. 2315 (NS), introduced April 9, 2020, would prohibit discrimination against living organ donors in relation to life, health, and long-term care insurance.

New York

• 2019 NY A.B. 971 (NS), introduced January 14, 2019, would require election for registration for organ, eye and tissue donations to be included upon certain state forms.

• 2019 NY A.B. 1133 (NS), amended/substituted June 5, 2019, would amend procedures for making anatomical gifts; specify persons authorized to make an anatomical gift under certain circumstances; provide procedures for amending and revoking gifts.

• 2019 NY A.B. 2123 (NS), introduced January 22, 2019, would prevent discrimination against persons with physical or mental disabilities in regards to organ donations.

• 2019 NY A.B. 2882 (NS), introduced January 28, 2019, would require election for registration for organ, eye, and tissue donations to be included upon certain state forms.

• 2019 NY A.B. 5785 (NS), amended/substituted June 11, 2019, relates to registering as an organ donor on SUNY, CUNY, and library card applications.

• 2019 NY A.B. 6805 (NS), introduced March 20, 2019, would establish the New York state brain donor registry.

• 2019 NY A.B. 6857 (NS), introduced March 22, 2019, would require election for registration for organ, eye, and tissue donations to be included upon applications for student loans and aid.

• 2019 NY A.B. 7800 (NS), amended/substituted June 14, 2019, would implement amended provisions of the Uniform Anatomical Gift Act as drafted by the National Conference of Commissioners on Uniform State Laws.

• 2019 NY A.B. 7915 (NS), adopted August 24, 2020, allowing donate life registration, consenting to make an anatomical gift, when applying for or renewing a hunting, fishing or trapping license.

• 2019 NY A.B. 7954 (NS), introduced May 29, 2019, would direct the Commissioner of Motor Vehicles to modify applications for driver's licenses and non-driver identification cards in a manner that deems consent to organ and tissue donation unless the applicant expressly elects not to consent.

• 2019 NY S.B. 1342 (NS), amended/substituted June 5, 2019, would amend procedures for making anatomical gifts, specifying persons authorized to make gifts under certain circumstances; would also provide procedures for amending or revoking gifts.

• 2019 NY S.B. 1491 (NS), amended/substituted May 28, 2019, and 2019 NY S.B. 141 (NS), introduced January 15, 2019, registering as an organ donor on SUNY, CUNY and library card applications.

• 2019 NY S.B. 3892 (NS), introduced February 20, 2019, relating to notification of the national bone marrow program.

• 2019 NY S.B. 4471 (NS), amended/substituted June 3, 2019, would allow donate life registration on applications for, or renewals of, fishing or trapping licenses.

• 2019 NY S.B. 5834 (NS), introduced May 15, 2019, relates to restoring medical futility as a basis for DNR.

• 2019 NY S.B. 6000 (NS), adopted December 26, 2019, implements amended provisions of the Uniform Anatomical Gift Act as drafted by the National Conference of Commissioners on Uniform State Laws.

• 2019 NY S.B. 6069 (NS), introduced May 16, 2019, would require election for registration for organ, eye and tissue donations to be included upon certain state forms.

• 2019 NY S.B. 6941 (NS), adopted April 17, 2020, to incorporate the amended provisions of the Uniform Anatomical Gift Act (UAGA) as drafted by the National Conference of Commissioners on Uniform State Laws, provides for anatomical gift duties of hospitals and procurement organizations; makes technical corrections.

• 2019 NY S.B. 7318 (NS), introduced January 17, 2020, would allow donate life registration when applying for or renewing a hunting, fishing or trapping license.

Ohio

2019 OH H.B. 41 (NS), introduced February 12, 2019, would prohibit long-term care and other insurers from discriminating against living organ donors.

Oklahoma

• 2019 OK H.B. 3358 (NS), introduced February 3, 2020, would create Janie's Gift Act providing for payment of funeral expenses by the State Department of Health for donors of anatomical gifts who do not have sufficient property or means to pay for funeral expenses; establishing the Janie's Gift Revolving Fund; providing for donations by individual income taxpayers into the revolving fund.

• 2019 OK S.B. 1359 (NS), engrossed on March 3, 2020, would provide for an authorizing court to order procurement of anatomical gifts under certain circumstances.

Pennsylvania

2019 PA H.B. 30 (NS), adopted November 25, 2020, in anatomical gifts, further providing for The Governor Robert P. Casey Memorial Organ and Tissue Donation Awareness Trust Fund contributions.

Tennessee

• 2019 TN H.B. 752 (NS), introduced February 5, 2019, and 2019 TN S.B. 1081 (NS), introduced February 7, 2019, would allow the recipient of an organ transplant and referral hospital to examine all genetic records of the donor or prospective donor unless prohibited by any other law.

• 2019 TN H.B. 2609 (NS), introduced February 5, 2020, would prohibits certain healthcare providers and entities from discriminating against qualified persons for receipt of transplantations or anatomical gifts based solely on disability; prohibits insurers that offer plans covering transplantations from denying coverage solely on disability.

• 2019 TN H.B. 2272 (NS), introduced February 5, 2020, would prohibit a procurement organization from procuring a body, or any part of a body, that a medical examiner is required by law to inspect until the medical examiner inspects the body and provides the procurement organization with written documentation that the inspection is complete.

• 2019 TN S.B. 2038 (NS), introduced February 3, 2020, would prohibit a procurement organization from procuring a body, or any part of a body, that a medical examiner is required by law to inspect until the medical examiner inspects the body and provides the procurement organization with written documentation that the inspection is complete.

• 2019 TN S.B. 2776 (NS), introduced February 6, 2020, would prohibits certain healthcare providers and entities from discriminating against qualified persons for receipt of transplantations or anatomical gifts based solely on disability; prohibits insurers that offer plans covering transplantations from denying coverage solely on disability.

Utah

2020 UT H.B. 349 (NS), introduced February 18, 2020, would prohibit an insurer from discriminating in the offering, issuance, cancellation, amount of coverage, price, or any other condition of a life insurance, accident and health insurance, or long-term care insurance policy or contract due to the status of an individual as a living organ donor.

Virginia

2020 VA H.B. 1273 (NS) and 2020 VA S.B. 846 (NS), adopted March 10, 2020, provides that an individual who is a candidate to receive an anatomical gift for organ, eye, or tissue transplantation and who is otherwise eligible to receive such gift shall not be deemed ineligible to receive an anatomical gift or denied services related to organ, eye, or tissue transplantation solely because of his physical, intellectual, developmental, or other disability.

Washington

2019 WA S.B. 6039 (NS), amended/substituted January 22, 2020, would prohibit insurers from declining or limiting coverage or otherwise discriminating in the offering, issuance, cancellation, amount of coverage, price or any other condition of a policy or contract for insurance due to the status of the person as a living organ donor.

West Virginia

2020 WV S.B. 257 (NS), introduced January 10, 2020, would prohibit discrimination in access to organ transplants, based on physical or mental disability.

Wyoming

2020 WY H.B. 233 (NS), introduced February 14, 2020, providing for donor designations on hunting and fishing licenses.

X. CONCLUSION

End-of-life issues remain at the forefront in 2019 as more and more states consider legislation to allow terminally ill patients to end their lives in a humane and dignified manner. More attention is focused on an aging population as baby boomers advance toward their later years. With a new health reform bill containing hospice provisions now in effect, reductions in annual marketbasket updates may impact hospice care over time. Meanwhile, related issues involving the definition and compliance requirements of advance care directives as well as improving the awareness of their existence through registries or other means remain under scrutiny in many states. Throughout 2019, HPTS will continue to monitor legislative and regulatory activity pertaining to hospice, palliative care, death with dignity initiatives, advance care directives, and other end-of-life care issues.

[FN2]

Report from: APA Working Group on Assisted Suicide and End-of-Life Decisions, available at: http://www.apa.org/pubs/info/reports/aseol.aspx#.

[FN3]

"Death and Dying: When is it time to let go?," *Reuters*, July 27, 2007, available at: www.cnn.com.

[FN4]

"Tracking the Care of Patients with Severe Chronic Illnesses," *The Dartmouth Atlas of Health Care 2008*, April 2008, available at: www.dartmouthatlas.org.

[FN5]

Kevin Sack, "In Hospice Care, Longer Lives Mean Money Lost," *The New York Times*, Nov. 27, 2007, at A1. 2007 WLNR 23393425.

[FN6]

Gail Gazelle, M.D., "Understanding Hospice?An Underutilized Option for Life's Final Chapter," *New England Journal of Medicine*, Volume 357, Issue 4, July 26, 2007. 2007 WLNR 14294983.

[FN7]

Harvard Medical School, "Hospice Care Under-Used by Many Terminally Ill Patients, Study Finds," Press Release, May 25, 2009, available at: http://web.med.harvard.edu/sites/RELEASES/html/052509_huskamp.html.

[FN8]

Kaiser Family Foundation *Daily Health Policy Report*, May 26, 2009, available at: www.kaisernetwork.org.

[FN9]

Rita Rubin, "Hospice Patients Feel Abandoned by Doctors; Study: Families of Dying People Want to Keep Contact, Too," *USA Today*, March 10, 2009, at 4D. 2009 WLNR 4537196.

[FN10]

"End-of-Life Care Talks Better for Patients and Budgets," *Oncology Nursing News*, June 19, 2009. http://www.oncologynursingnews.com/End-Of-Life-Care-Talks-Better-For-Patients-And-Budgets/article/137327/.

[FN11]

"Survey: 62% hesitant to discuss end of life care," WBJournal.com, May 17, 2017, available at: http://www.wbjournal.com/article/20170517/NEWS01/170519942.

[FN12]

Emily Mongan, "Researchers dissect end-of-life care practices, issue best practices," *McKnights*, available at: http://www.mcknights.com/news/researchers-dissect-end-of-life-care-practices-issue-best-practices/article/572877/.

[FN13]

Nauzley C. Abedini et al., “The Relationship of Loneliness to End-of-Life Experience in Older Americans: A Cohort Study,” *Journal of the American Geriatrics Society*, Wiley Online Library (Mar. 3, 2020), available at: https://onlinelibrary.wiley.com/doi/abs/10.1111/jgs.16354.

[FN14]

Ricardo Alonso-Zaldivar, “Nursing home COVID-19 cases rise four-fold in surge states,” *AP* (Nov. 8, 2020), available at: https://apnews.com/article/virus-outbreak-only-on-ap-chicago-nursing-homes-596ef4bfe18313ae72368e2c86e85f27.

[FN15]

Robert T. Stafford Disaster Relief and Emergency Assistance Act, 42 U.S.C. ?? 5121?5207.

[FN16]

Trump Administration Makes Sweeping Regulatory Changes to Help U.S. Healthcare System Address COVID-19 Patient Surge, CMS.gov (press release, Mar. 30, 2020), available at: https://www.cms.gov/newsroom/press-releases/trump-administration-makes-sweeping-regulatory-changes-help-us-healthcare-system-address-covid-19.

[FN17]

COVID-19 Emergency Declaration Blanket Waivers for Health Care Providers (fact sheet), CMS.gov (Apr. 3, 2020), available at: https://www.cms.gov/files/document/covid19-emergency-declaration-health-care-providers-fact-sheet.pdf.

[FN18]

Jim Parker, ‘CMS to Resume Audits, Medical Reviews in August,’ *Hospice News* (July 16, 2020), available at: https://hospicenews.com/2020/07/16/cms-to-resume-audits-medical-reviews-on-aug-3/.

[FN19]

Vanessa Romo, “For Most States, At Least A Third Of COVID-19 Deaths Are In Long-Term Care Facilities,' *NPR.org* (May 9, 2020), available at: https://www.npr.org/sections/coronavirus-live-updates/2020/05/09/853182496/for-most-states-at-least-a-third-of-covid-19-deaths-are-in-long-term-care-facili.

[FN20]

State Data and Policy Actions to Address Coronavirus, *KFF* (May 15, 2020), available at: https://www.kff.org/health-costs/issue-brief/state-data-and-policy-actions-to-address-coronavirus/.

[FN21]

'43 percent of U.S. virus deaths are tied to nursing homes and long-term care facilities,' *The New York Times* (June 29, 2020), available at: https://www.nytimes.com/2020/06/29/world/coronavirus-updates.html#link-c785897.

[FN22]

'43% of U.S. Coronavirus Deaths Are Linked to Nursing Homes,' *The New York Times* (June 27, 2020), available at: https://www.nytimes.com/interactive/2020/us/coronavirus-nursing-homes.html

[FN23]

Medicare and Medicaid Programs, Basic Health Program, and Exchanges; Additional Policy and Regulatory Revisions in Response to the COVID-19 Public Health Emergency and Delay of Certain Reporting Requirements for the Skilled Nursing Facility Quality Reporting Program, Centers for Medicare & Medicaid Services, 85 FR 27550 (May 8, 2020), available at: https://www.federalregister.gov/documents/2020/05/08/2020-09608/medicare-and-medicaid-programs-basic-health-program-and-exchanges-additional-policy-and-regulatory.

[FN24]

The guidelines can be found at https://www.cdc.gov/coronavirus/2019-ncov/hcp/index.html.

[FN25]

Coronavirus Disease 2019 (COVID-19), Information for Healthcare Professionals, Centers for Disease Control and Prevention, available at: https://www.cdc.gov/coronavirus/2019-nCoV/hcp/index.html.

[FN26]

Frequently Asked Questions (FAQs) on Nursing Home Visitation, CMS.gov (June 23, 2020), available at: https://www.cms.gov/files/document/covid-visitation-nursing-home-residents.pdf.

[FN27]

Seema Verma, 'Early Impact Of CMS Expansion Of Medicare Telehealth During COVID-19,' *Health Affairs* (July 15, 2020), available at: https://www.healthaffairs.org/do/10.1377/hblog20200715.454789/full/?utm_source=Master+Segment+List&utm_campaign=dba6a3df80-EMAIL_CAMPAIGN_2020_07_16_07_32&utm_medium=email&utm_term=0_9b5a8c75fe-dba6a3df80-150888080&.

[FN28]

Kristin Easterling, 'What is the Protecting Access to Post-COVID-19 Telehealth Act?,' *HomeCare* (July 28, 2020), available at: https://www.homecaremag.com/august-2020/protecting-access-post-covid19-telehealth-act.

[FN29]

Hospice in the Time of COVID-19: Findings from the NAHC National Survey, *National Association for Home Care & Hospice* (press release, May 27, 2020), available at: https://www.nahc.org/2020/05/27/hospice-in-the-time-of-covid-19-findings-from-the-nahc-national-survey/.

[FN30]

Douglas B. White, MD, MAS, and Bernard Lo, MD, 'A Framework for Rationing Ventilators and Critical Care Beds During the COVID-19 Pandemic,' *JAMA Network*, (Mar. 27, 2020), available at: https://jamanetwork.com/journals/jama/fullarticle/2763953.

[FN31]

Trump Administration Acts to Ensure U.S. Healthcare Facilities Can Maximize Frontline Workforces to Confront COVID-19 Crisis, C*MS.gov* (Press release, Apr. 9, 2020), available at: https://www.cms.gov/newsroom/press-releases/trump-administration-acts-ensure-us-healthcare-facilities-can-maximize-frontline-workforces-confront.

[FN32]

Alicia Lasek, 'Parkinson: On-site COVID-19 testing could be key to reducing ?horrible' isolation facing residents,' *McKnight's Long-term Care News* (May 26, 2020), available at: https://www.mcknights.com/news/clinical-news/parkinson-on-site-covid-19-testing-could-be-key-to-reducing-horrible-isolation-facing-residents/.

[FN33]

The interview is available in its entirety on YouTube, at https://www.youtube.com/watch?v=uBbmPMQvk4I.

[FN34]

William Wan, 'Pandemic isolation has killed thousands of Alzheimer's patients while families watch from afar,' *The Washington Post* (Sept. 16, 2020), https://www.washingtonpost.com/health/2020/09/16/coronavirus-dementia-alzheimers-deaths/?arc404=true.

[FN35]

"Nonprofit Hospice Services: Where Mission and Community Meet," LeadingAge, LeadingAge Ohio, and the National Partnership for Hospice Innovation. (January 2019), available at: https://www.leadingage.org/sites/default/files/Nonprofit#ospiceS#ervices_FINAL5#.pdf.

[FN36]

"Report: Watching Videos of the End of Life Helps People Make Care Choices," *McKnight's Long-Term Care News and Assisted Living*, June 2, 2009, available at: www.mcknights.com.

[FN37]

Cathy Lynn Grossman, "Life and Death: Hospital Ethics Panels Help Families Decide," *USA Today*, Oct. 7, 2009, available at: http://www.usatoday.com/news/religion/2009-10-07-death-decisions_N.htm.

[FN38]

"Chronically Ill? Give up Hope, Researchers Say," *McKnight's Long-Term Care News & Assisted Living*, Nov. 4, 2009, available at: http://www.mcknights.com/Chronically-ill-Give-up-hope-researchers-say/article/157020/.

[FN39]

"New Website Launched to Raise Awareness of Palliative Care," *The Medical News*, Aug. 24, 2009, available at: http://www.news-medical.net/news/20090824/New-website-launched-to-raise-awareness-of-palliative-care.aspx.

[FN40]

Bestow Team, “What States Are Most Concerned About End-of-Life Issues?,” Bestow (Dec. 14, 2018), available at: https://hellobestow.com/blog/states-concerned-about-end-of-life/.

[FN41]

Centers for Medicare & Medicaid Services, “CMS Outlines Rights of Medicare Hospice Patients: First Overhaul Since 1983 Aimed at Improving Quality of Care,” Press Release, June 3, 2008, available at: www.cms.hhs.gov.

[FN42]

Alicia Ault, “For Hospice, A Higher Authority,” *The Washington Post*, July 1, 2008, available at: www.washingtonpost.com.

[FN43]

73 FR 32088-01, 2008 WL 2277001.

[FN44]

Robert Pear and David M. Herszenhorn, “Democrats Push Health Care Plan While Issuing Assurances on Medicare,” *The New York Times*, July 28, 2009, available at: http://www.nytimes.com/2009/07/29/health/policy/29health.html.

[FN45]

Ricardo Alonso-Zaldivar, “Administration Reverses on End-of-Life Counseling,” *AP DataStream*, January 5, 2011. 1/5/11 APDATASTREAM 19:10:18.

[FN46]

Lucas Morin, et al., “Discussing end-of-life issues in nursing homes: a nationwide study in France, *Age and Ageing* (3/24/2016), available at: http://ageing.oxfordjournals.org/content/early/2016/03/24/ageing.afw046.abstract?sid=4a860ed7-cdb0-4b97-9088-cd858303a17e.

[FN47]

Kathryn Doyle, End of life planning does not make cancer patients hopeless or anxious, Reuters (Jan. 2, 2015).

[FN48]

“How Life Ends for Cancer Patients Depends on the Hospital,” NPR, Nov. 16, 2010, available at: http://www.npr.org/blogs/health/2010/11/16/131361970/how-life-ends-for-cancer-patients-depends-on-the-hospital.

[FN49]

Anemona Hartocollis, “Hospital Care at Life's End: A Disparity,” *New York Times*, April 12, 2011. 2011 WLNR 7038485.

[FN50]

E.J. Mundell, “Cultural Beliefs May Keep Blacks from Hospice Care,” *Health Day*, Feb. 5, 2008. 2008 WLNR 2163496.

[FN51]

Lee Hancock, “Program Encourages Black Families to Embrace End-of-Life Care,” *The Dallas Morning News*, June 28, 2008. 2008 WLNR 12280990.

[FN52]

“End-of-Life Care Differs by Race: Study,” *Reuters Health*, Jan. 30, 2009, available at: www.reutershealth.com.

[FN53]

“Blacks' End-of-Life Care Preferences Often Overlooked, Study Finds,” McKnight's Long-Term Care News & Assisted Living, Sept. 28, 2010, available at: http://www.mcknights.com/blacks-end-of-life-care-preferences-often-overlooked-study-finds/article/179751/.

[FN54]

“Racial Differences in End-of-Life Planning: Why Don't Blacks and Latinos Prepare for the Inevitable? Rutgers researcher explores cultural attitudes toward death and family,” Rutgers News Release (July 20, 2012). Available at: http://news.rutgers.edu/medrel/news-releases/2012/07/racial-differences-i-20120717/.

[FN55]

Fredrick Kunkle, Ethnicity complicates patient-doctor discussion of death, WashingtonPost.com (April 22, 2015) at 2015 WLNR 11726999.

[FN56]

Katherine A. Ornstein, et al., Evaluation of Racial Disparities in Hospice Use and End-of-Life Treatment Intensity in the REGARDS Cohort, *JAMA Network Open* (Aug. 24, 2020), available at: https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2769692.

[FN57]

"Nursing Home Dementia Residents Staying in Hospice Longer, Analysis Says," McKnight's Long-Term Care News & Assisted Living, Dec. 16, 2010, available at: http://www.mcknights.com/nursing-home-dementia-residents-staying-in-hospice-longer-analysis-says/article/192895/.

[FN58]

Serena Gordon, "Study Casts Doubt on Hospice Admission Criteria for Patients with Dementia," Bloomberg Businessweek, Nov. 2, 2010, available at: http://www.businessweek.com/lifestyle/content/healthday/645309.html.

[FN59]

"People with dementia more likely to die at home than a facility," *McKnight's Long Term Care News & Assisted Living* (May 14, 2012). Available at: http://www.mcknights.com/people-with-dementia-more-likely-to-die-at-home-than-a-facility/article/240869/?DCMP=EMC-MCK_Weekly.

[FN60]

Available at: http://onlinelibrary.wiley.com/doi/10.1111/j.1532-5415.2012.03905.x/abstract.

[FN61]

Press Release, Hospice Use Linked to Fewer Depressive Symptoms for Surviving Spouses, Mount Sinai Hospital (May 26, 2015).

[FN62]

"Where People Die Matters. Hint: Not the ICU," The Los Angeles Times, Sept. 14, 2010, available at: http://www.latimes.com/health/boostershots/la-heb-hospital-death-20100914,0,6438747.story?track=rss.

[FN63]

Zhang B, Nilsson ME, Prigerson HG, "Factors Important to Patients; Quality of Life at the End of Life," *Archives of Internal Medicine* (July 9, 2012). Available at: http://archinte.jamanetwork.com/article.aspx?articleid=1212635.

[FN64]

Joan M. Teno, et al., "Change in End-of-Life Care for Medicare Beneficiaries?Site of Death, Place of Care, and Health Care Transitions in 2000, 2005, and 2009." *JAMA* (Feb. 6, 2013, Vol. 309, No. 5), available at: http://jama.jamanetwork.com/article.aspx?articleid=1568250#ref-joc120140-3.

[FN65]

Anna Gorman, "?Pre-Hospice' Saves Money By Keeping People At Home Near The End of Life," *Kaiser Health News* (March 27, 2017), available at: khn.org/news/pre-hospice-saves-money-by-keeping-people-at-home-near-the-end-of-life/.

[FN66]

The rule is available at http://www.gpo.gov/fdsys/pkg/FR-2013-06-27/pdf/2013-15313.pdf.

[FN67]

Roxanne Nelson, "Smart Technology Helps Cancer Pts and Caregivers in Hospice," Medscape Medical News (Oct. 23, 2014), available at: http://www.medscape.com/viewarticle/833734.

[FN68]

"Impact of Hospice Use on Costs of Care for Long Stay Nursing Home Decedents" is published online ahead of print in the *Journal of the American Geriatrics Association* and is available, for a fee, at: http://onlinelibrary.wiley.com/doi/10.1111/jgs.14070/abstract.

[FN69]

Impact of Nursing Shortage on Hospice Care (memorandum), Centers for Medicare & Medicaid Services (Oct. 21, 2016), available at: https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/Downloads/Survey-and-Cert-Letter-17-01.pdf.

[FN70]

Susan C. Miller et al., “Increasing Veterans' Hospice Use: The Veterans Health Administration's Focus On Improving End-Of-Life Care,” *Health Affairs*, vol. 36, no. 7, 1274?82 (July 2017), available at: http://content.healthaffairs.org/content/36/7/1274.abstract?=right.

[FN71]

Orna Intrator, et al., Benchmarking Site of Death and Hospice Use: A Case Study of Veterans Cared by Department of Veterans Affairs Home-based Primary Care, *Medical Care* (Sept. 2020), available at: https://journals.lww.com/lww-medicalcare/Abstract/2020/09000/Benchmarking_Site_of_Death_and_Hospice_Use__A_Case.8.aspx.

[FN72]

Holly Vossol, More Veterans Gravitating Toward Home-Based Hospice Care, *Hospice News* (Oct. 29, 2020), available at: https://hospicenews.com/2020/10/29/more-veterans-gravitating-toward-home-based-hospice-care/.

[FN73]

“End-of-life care quality remains a problem?nurses may be a solution,” University of Pennsylvania School of Nursing, Public Release, *EurekaAlert!* (Dec. 17, 2018), available at: https://www.eurekalert.org/pub_releases/2018-12/uops-eol121718.php.

[FN74]

“Hospice Deficiencies Pose Risks to Medicare Beneficiaries,” U.S. Department of Health and Human Services Office of Inspector General (OEI-02-17-00020, July 2019), available at: https://oig.hhs.gov/oei/reports/oei-02-17-00020.pdf?utm_source=summary-page&utm_medium=web&utm_campaign=OEI-02-17-00020-PDF.

[FN75]

Hospice Performance on Health and Safety Surveys?Concerns and Considerations, A NAHC Information Brief, *National Association for Home Care & Hospice*, available at: https://www.nahc.org/wp-content/uploads/2019/09/HOSPICE-PERFORMANCE-ON-HEALTH-SAFETY-SURVEYS-Concerns-Recommendations.pdf.

[FN76]

Jim Parker, “Bill Would Allow Hospice Recertification Via Telehealth,” *Hospice News* (Oct. 31, 2019), available at: https://hospicenews.com/2019/10/31/bill-would-allow-hospice-recertification-via-telehealth/.

[FN77]

The study was published in the *New England Journal of Medicine*, 381:2369-2370 (Dec. 12, 2019), available at: https://2019 / cwww.nejm.org/doi/full/10.1056/NEJMc1911892.

[FN78]

Fiscal Year 2021 Hospice Payment Rate Update Final Rule CMS-1733-F, *CMS.gov* (Fact sheet, July 31, 2020), available at: https://www.cms.gov/newsroom/fact-sheets/fiscal-year-2021-hospice-payment-rate-update-final-rule-cms-1733-f.

[FN79]

Jim Parker, '53 Medicare Advantage Plans to Offer Hospice in 2021, Palliative Care to Grow,' *Hospice News* (Sept. 25, 2020), available at: https://hospicenews.com/2020/09/25/53-medicare-advantage-plans-to-offer-hospice-in-2021-palliative-care-to-growß°–/.

[FN80]

Tim Mullaney, “CMS updates coding instructions for hospice site of service, principal diagnosis,” *McKnight's Long-term Care & Assisted Living* (Sept. 2, 2014), available at http://www.mcknights.com/cms-updates-coding-instructions-for-hospice-site-of-service-principal-diagnosis/article/368893/. Full text of the MLN memorandum is available at http://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNMattersArticles/Downloads/MM8877.pdf.

[FN81]

A fact sheet on the Medicare Care Choices Model is available at: http://www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2014-Fact-sheets-items/2014-03-18.html.

[FN82]

76 FR 47302, 2011 WL 3322765.

[FN83]

Medicare Program; FY 2018 Hospice Wage Index and Payment Rate Update and Hospice Quality Reporting Requirements, Centers for Medicare & Medicaid Services, 82 Fed. Reg. 36638 (Aug. 4, 2017). 2017 WL 3311409.

[FN84]

“Vulnerabilities in the Medicare Hospice Program Affect Quality Care and Program Integrity,” U.S. Department of Health and Human Services, Office of Inspector General (Portfolio in Brief, July 2018, OEI-02-16-00570), available at: https://oig.hhs.gov/oei/reports/oei-02-16-00570.pdf.

[FN85]

The Hospice PUF is available at: https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Medicare-Provider-Charge-Data/Hospice.html. To view a fact sheet on the Hospice PUF, visit: https://www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2016-Fact-sheets-items/2016-10-06.html.

[FN86]

The Market Saturation and Utilization Data Tool is available at: https://data.cms.gov/market-saturation.

[FN87]

Visualizing Health Policy: Medicare and End-of-Life Care, *The Henry J. Kaiser Family Foundation* (Nov. 1, 2016), available at: http://kff.org/infographic/visualizing-health-policy-medicare-and-end-of-life-care/.

[FN88]

“Healthcare Market Resources Releases In-Depth Study on Future Hospice Utilization,” PRWeb, Oct. 26, 2010, available at: http://www.prweb.com/releases/prweb2010/10/prweb4681184.htm.

[FN89]

Anemona Hartocollis, “Hospital Care at Life's End: A Disparity,” *New York Times*, April 12, 2011. 2011 WLNR 7038485.

[FN90]

Dorothy Brooten et al., “Parent's Perceptions of Health Care Providers Actions Around Child ICU Death: What Helped, What Did Not,” *The American Journal of Hospice & Palliative Care* (Feb. 2013, 30:40-9), *available at*: http://ajh.sagepub.com/content/30/1.toc.

[FN91]

Amy S. Kelley et al., “Hospice Enrollment Saves Money for Medicare and Improves Care Quality Across a Number of Different Lengths-Of-Stay,” *Health Affairs* (March 2013, vol. 32 no. 3, 552-561), available at: http://content.healthaffairs.org/content/32/3/552.abstract.

[FN92]

Full text of the report is available at http://www.dartmouthatlas.org/downloads/reports/Cancer_brief_090413.pdf.

[FN93]

“Hospice Providers May Have Financial Reasons to Discourage Enrollment of Certain Patients,” The Washington Post (Blog, Jan. 22, 2013). 2013 WLNR 1649264.

[FN94]

Nan Tracy Zheng et al., “The Effect of Hospice on Hospitalizations of Nursing Home Residents,” *Journal of the American Medical Directors Association* (Oct. 8, 2014), available at: http://www.sciencedirect.com/science/article/pii/S152586101400543X.

[FN95]

To read a fact sheet about the model, including a list of participants visit: http://www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2015-Fact-sheets-items/2015-07-20.html.

[FN96]

The website is available at: https://www.medicare.gov/hospicecompare/.

[FN97]

Hospice Quality Reporting, CMS.gov, https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Hospice-Quality-Reporting/Hospice-Quality-Public-Reporting.html.

[FN98]

“Federal Courts Continue to Invalidate Hospice Reimbursement Caps,” *McKnight's Long-Term Care News & Assisted Living* (Mar. 8, 2011), available at: http://www.mcknights.com/federal-courts-continue-to-invalidate-hospice-reimbursement-caps-/article/197810/?DCMP=EMC-MCK_Weekly.

[FN99]

“Court: Medicare hospice provider cap calculated improperly,” *McKnight's Long-Term Care News & Assisted Living* (Mar. 4, 2011), available at: http://www.mcknights.com/court-medicare-hospice-provider-cap-calculated-improperly/article/165032.

[FN100]

Tranquility Hospice Inc. v. Sebelius, N.D. Okla., No. 4:11-cv-00324-TCK-TLW, 7/24/12.

[FN101]

David Pardo, “Medicare: Oklahoma Hospice Challenges HHS Rule, Court Stops $1.2M Overpayment Recoupment,” *BNA's Health Care Daily Report* (July 27, 2012). 2012 WL 3040598 (B.N.A.).

[FN102]

Emily Mongan, “Supreme Court declines review of Medicare hospice cap case,” *McKnight's* (Oct. 3, 2016), available at: http://www.mcknights.com/news/supreme-court-declines-review-of-medicare-hospice-cap-case/article/526628/.

[FN103]

Southeast Arkansas Hospice, Inc. v. Burwell, 815 F.3d 448 (8th Cir. 2016).

[FN104]

Study: Nursing Homes Increasingly Pushing Patients into Rehab at End-of-Life, University of Rochester Medical Center (Newsroom, Oct. 3, 2018), available at: https://www.urmc.rochester.edu/news/story/5434/study-nursing-homes-increasingly-pushing-patients-into-rehab-at-end-of-life.aspx.

[FN105]

JoNel Aleccia, “End-Of-Life Advice: More Than 500,000 Chat On Medicare's Dime,” *Kaiser Health News* (Aug. 14, 2017), available at: http://khn.org/news/end-of-life-advice-more-than-500000-chat-on-medicares-dime/.

[FN106]

The rule is available at 79 FR 50452-01, 2014 WL 4104965 (F.R.).

[FN107]

Accepting Hospice Notices of Election via Electronic Data Interchange, CMS Manual System, Pub 100-04 Medicare Claims Processing Transmittal 3813, Change Request 10064 (July 27, 2017), available at: https://www.cms.gov/Regulations-and-Guidance/Guidance/Transmittals/2017Downloads/R3813CP.pdf.

[FN108]

Lisa Rapaport, “Delayed hospice care common for dialysis patients,” *Reuters* (May 23, 2018), available at: https://www.reuters.com/article/us-health-kidneyfailure-hospice-costs/delayed-hospice-care-common-for-dialysis-patients-idUSKCN1IO3AE.

[FN109]

The report is available at: https://oig.hhs.gov/oei/reports/oei-02-10-00490.asp.

[FN110]

Robert Pear, “Researchers Find Huge Variations in End-of-Life Treatment,” *The New York Times*, April 7, 2008, at A17. 2008 WLNR 6484006. View the *Dartmouth Atlas of Health Care 2008* report at: www.dartmouthatlas.org.

[FN111]

Anne Harding, “End-of-life care costs continue to climb,” *Chicago Tribune* (Oct. 14, 2010). 2010 WLNR 20522769.

[FN112]

“Ancillary costs pound seniors,” *McKnight's Long-Term Care News & Assisted Living* (Oct. 1, 2012), available at: http://www.mcknights.com/ancillary-costs-pound-seniors/article/262537/.

[FN113]

Liz Szabo, “Treatment Overkill: Never Too Late To Operate? Surgery Near End of Life Is Common, Costly,” *Kaiser Health News* (Feb. 28, 2018), available at: https://khn.org/news/never-too-late-to-operate-surgery-near-end-of-life-is-common-costly/, *citing* Alvin C. Kwok, et al., “The intensity and variation of surgical care at the end of life: a retrospective cohort study,” *The Lancet* (Oct. 6, 2011), available at: http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(11)61268-3/fulltext.

[FN114]

“Critics of Nursing-Home Hospices Suspicious of Revenue,” *McKnight's Long-Term Care News & Assisted Living* (Jan. 31, 2011), available at: http://www.mcknights.com/critics-of-nursing-home-hospices-suspicious-of-revenue/article/195240/?DCMP=EMC-MCK_Weekly.

[FN115]

Brett Coughlin, “Hospice Care Prompts Profits, Probe,” POLITICO, Jan. 27, 2011, available at: http://www.politico.com/news/stories/0111/48304.html.

[FN116]

The report, “Medicare Hospices That Focus on Nursing Facility Residents, Daniel R. Levinson, Inspector General,” July 2011, OEI-02-10-00070, is available at: http://oig.hhs.gov/oei/reports/oei-02-10-00070.pdf.

[FN117]

“Inspector general recommends lower Medicare payment rates to nursing home hospices,” *McKnight's Long-Term Care News & Assisted Living*, July 22, 2011, available at: www.mcknights.com/inspector-general-recommends-lower-medicare-payment-rates-to-nursing-home-hospices/article/208084/?DCMP=EMC-MCK_ Daily.

[FN118]

CMS Manual System, Pub 100-04 Medicare Claims Processing, Transmittal 2864, *available at:* http://www.cms.gov/Regulations-and-Guidance/Guidance/Transmittals/2014-Transmittals-Items/R2864CP.html?DLPage=1&DLSort=1&DLSortDir=descending.

[FN119]

Medicare Could Be Paying Twice for Prescription Drugs for Beneficiaries in Hospice (A-06-10-00059), available at: http://oig.hhs.gov/oas/reports/region6/61000059.pdf.

[FN120]

Mindy Yochelson, “Part D Drug Benefit: OIG Says Medicare May Be Paying Twice for Some Drugs Under Hospice Benefit,” BNA's Health Care Daily Report (July 6, 2012). 2012 WL 2586530 (B.N.A.).

[FN121]

“Advance directives mean more palliative, less costly care, study shows,” *McKnight's Long-Term Care News & Assisted Living* (Oct. 7, 2011), available at: http://www.mcknights.com/advance-directives-mean-more-palliative-less-costly-care-study-shows/article/213793/.

[FN122]

The Full text of the rule is available at 7 FR 67068-01, 2012 WL 5425290 (F.R.).

[FN123]

“CMS's Reliance on Illinois Licensure Requirements Could not Ensure the Quality of Care Provided to Medicaid Hospice Beneficiaries,” Department of Health and Human Services Office of Inspector General (A-05-12-00028, June 2014), available at: http://oig.hhs.gov/oas/reports/region5/51200028.pdf.

[FN124]

Teno, Joan M., MD, et al., “Examining Variation in Hospice Visits by Professional Staff in the Last 2 Days of Life,” *JAMA Internal Medicine* (February 8, 2016), http://archinte.jamanetwork.com/article.aspx?articleid=2488922.

[FN125]

Peter Whoriskey & Dan Keating, “Hospice firms draining billions from Medicare,” *The Washington Post* (Dec. 27, 2013). 2013 WLNR 32230110.

[FN126]

Medicare Hospices Have Financial Incentives To Provide Care in Assisted Living Facilities (OEI-02-14-00070) at: http://oig.hhs.gov/oei/reports/oei-02-14-00070.asp.

[FN127]

John Wilkerson, “MedPAC Draft Recommendation Would Cut Pay To Employer MA Plans,” *Inside CMS* (Vol. 17, Issue 4, Jan. 23, 2014). 2014 WLNR 1990257.

[FN128]

Final Fiscal Year 2017 Payment and Policy Changes for the Medicare Hospice Benefit (CMS-1652-F), CMS fact sheet (July 29, 2016), available at: https://www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2016-Fact-sheets-items/2016-07-29-2.html.

[FN129]

Ziad Obermeyer et al., "Association Between the Medicare Hospice Benefit and Health Care Utilization and Costs for Patients with Poor-Prognosis Cancer," *JAMA* (Vol. 312, No. 18, Nov. 12, 2014), available through subscription or purchase at: http://jama.jamanetwork.com/article.aspx?articleid=1930818&resultClick=1.

[FN130]

"Effect of use of hospice care by Medicare patients on hospitalizations and costs, Palliative and Supportive Care," *NewsRx Science* (Nov. 30, 2014, loaded date: Nov. 20, 2014). 2014 WLNR 32724190.

[FN131]

Jordan Rau, "Treatment and Hospice Simultaneously," *The Philadelphia Inquirer*, May 10, 2010, available at: http://www.philly.com/inquirer/health_science/weekly/20100510_Treatment_and_hospice_simultaneously.html#axzz0npswYe9X.

[FN132]

74 FR 13439-01, 2009 WL 789811.

[FN133]

The Joint Commission, "CMS Recognizes the Joint Commission for Continued Hospice Deeming Authority," Press Release, April 9, 2009, available at: www.jointcommission.org.

[FN134]

See 78 Fed. Reg. 66364 (Nov. 5, 2013). 2013 WL 5888354 (F.R.).

[FN135]

Rachel Bluth, "Younger Seniors Amass More End-Of-Life Care Than Oldest Americans, Study Finds," *Kaiser Health News* (July 14, 2016), available at: http://khn.org/news/younger-seniors-amass-more-end-of-life-care-than-oldest-americans-study-finds/.

[FN136]

Law for Older Americans: Health Care Advance Directives, American Bar Association, Division for Public Education, available at: https://www.americanbar.org/groups/public_education/resources/law_issues_for_consumers/patient_self_determination_act.html.

[FN137]

Pub. L. 109-3 (March 21, 2005).

[FN138]

See Bush v. Schiavo, 885 So.2d 321 (Fla. 2004), cert. denied, 125 S.Ct. 1086 (2005); *Schiavo ex rel. Schindler v. Schiavo,* 403 F.3d 1223 (11th Cir. 2005), cert. denied, 125 S.Ct. 1692 (2005); *Schiavo ex rel. Schindler v. Schiavo,* 403 F.3d 1289 (11th Cir. 2005), cert. denied, 125 S.Ct. 1722 (2005).

[FN139]

AARP Bulletin Poll, "Getting Ready to Go," Executive Summary, January 2008, available at: www.aarp.org/research/endoflife/issues/getting_ ready.html.

[FN140]

Emily Mongan, "Researchers dissect end-of-life care practices, issue best practices," *McKnights* (November 14, 2016), available at: http://www.mcknights.com/news/researchers-dissect-end-of-life-care-practices-issue-best-practices/article/572877/.

[FN141]

"Legal Restrictions Compromise Effectiveness of Advance Directives," *U.S. Federal News*, January 4, 2011.

[FN142]

Mariette L. Klein, "Dementia Caregivers: An Exploration of Their Knowledge, Beliefs, and Behavior Regarding Advance Care Planning for End-of-Life Care" (dissertation), Virginia Commonwealth University, Richmond, Va., May 2014, *available at*: https://digarchive.library.vcu.edu/handle/10156/4665.

[FN143]

“End-of-Life Care Could Depend on Physician's Religion, Study Suggests,” *McKnight's Long-Term Care News & Assisted Living* (Aug. 30, 2010), available at: http://www.mcknights.com/end-of-life-care-could-depend-on-physicians-religion-study-suggests/article/177704/.

[FN144]

Jordan Rau, “Treatment and Hospice Simultaneously,” *The Philadelphia Inquirer*, May 10, 2010, available at: http://www.philly.com/inquirer/health_science/weekly/20100510_Treatment_and_hospice_simultaneously.html#axzz0npswYe9X.

[FN145]

“New Guidelines Released for Hospice Patients with Defibrillators,” *McKnight's Long-Term Care News & Assisted Living* (May 17, 2010), available at: http://www.mcknights.com/new-guidelines-released-for-hospice-patients-with-defibrillators/article/170238/.

[FN146]

News Release, Odds of Reversing ICU Patients' Prior Preferences to Forgo Life-Sustaining Therapies Vary Widely Across the U.S., according to Penn Study, Penn Medicine (March 30, 2015).

[FN147]

News Release, Linked: Knowledge of palliative care and less end-of-life disruption, Brown University (March 20, 2015).

[FN148]

Kathryn Doyle, Unrelated ‘next of kin’ may lead to legal confusion, Reuters (April 7, 2015).

[FN149]

“Advance directives mean more palliative, less costly care, study shows,” *McKnight's Long-Term Care News & Assisted Living* (Oct. 7, 2011), available at: http://www.mcknights.com/advance-directives-mean-more-palliative-less-costly-care-study-shows/article/213793/.

[FN150]

Joe Rojas-Burke, “End-of-life Orders Bias Health Care, Study Finds,” *The Oregonian*, January 4, 2012. 2012 WLNR 306907.

[FN151]

JoNel Aleccia, “End-Of-Life Advice: More Than 500,000 Chat On Medicare's Dime,” *Kaiser Health News* (Aug. 14, 2017), available at: http://khn.org/news/end-of-life-advice-more-than-500000-chat-on-medicares-dime/.

[FN152]

“New Research Reveals What to Discuss Near Life's End,” McMaster University, *NewsRx Health & Science* (Nov. 23, 2014). 2014 WLNR 3196054.

[FN153]

Enrique Rivero, “Nearly half of California nursing home residents complete end-of-life care orders,” UCLA Newsroom (July 8, 2016), available at: “http://newsroom.ucla.edu/releases/nearly-half-of-california-nursing-home-residents-complete-end-of-life-care-orders.

[FN154]

Amy Novotney, “Advance directive app wins HHS tech competition,” *McKnight's* (July 6, 2017), available at: http://www.mcknights.com/news/advance-directive-app-wins-big-in-hhs-tech-competition/article/671602/.

[FN155]

James T. Mulder, “Syracuse nursing home faulted for saving woman who did not want to be saved,” syracuse.com (Jan. 9, 2018), available at: http://www.syracuse.com/health/index.ssf/2018/01/syracuse_nursing_home_censured_for_saving_woman_who_did_not_want_to_be_saved.html.

[FN156]

JoNel Aleccia, “?Aggressive' New Advance Directive Would Let Dementia Patients Refuse Food',” *Kaiser Health News* (March 30, 2018), available at: https://khn.org/news/aggressive-new-advance-directive-would-let-dementia-patients-refuse-food/.

[FN157]

Sheryl Crosier, “The Story Behind Simon's Law and Parental Rights Over DNRs,” Pro-Life Healthcare Alliance (July 2, 2018), available at: https://www.prolifehealthcare.org/story-simons-law-parental-rights-dnrs/.

[FN158]

“Simon's Law,” American College of Pediatricians, available at: https://www.acpeds.org/the-college-speaks/for-policy-makers/sanctity-of-life/simons-law.

[FN159]

“Program to support advance care planning in nursing homes expands to multiple states,” *Regenstrief Institute* (Dec. 10, 2019), available at: https://www.regenstrief.org/article/nursing-home-advance-care-planning-program-expands/.

[FN160]

Kaiser Family Foundation *Daily Health Policy Report,* April 26, 2007, available at: www.kaisernetwork.org.

[FN161]

Joanne Kenen, “A New Focus on Easing the Pain,” *The Washington Post*, July 3, 2007, available at: www.washingtonpost.com/wp-dyn/content/article/2007/06/29/AR2007062902064.html.

[FN162]

“Palliative Care Programs Could Boost Hospitals' Bottom Line,” *U.S. News & World Report*, Sept. 12, 2008. 2008 WLNR 17362193.

[FN163]

“National Hospice and Palliative Care Organization, “National Hospice and Palliative Care Organization Calls for Increased Access to Palliative Care in Critical Care Settings,” Press Release, Sept. 4, 2008, available at: http://www.nhpco.org/i4a/pages/index.cfm?pageid=5715.

[FN164]

Jim Parker, “Palliative Care Could Cut Health Care Costs by $103 Billion,” *Hospice News* (Apr. 4, 2019), available at: https://hospicenews.com/2019/04/04/palliative-care-could-cut-health-care-costs-by-103-billion/.

[FN165]

Diane E. Meier et al., “A National Strategy for Palliative Care,” *Health Affairs* (July 2017) (abstract), available at: https://www.healthaffairs.org/doi/abs/10.1377/hlthaff.2017.0164?rfr_dat=cr_pub#pubmed&url_ver=Z39.88-2003&rfr_id=ori#rid#crossref.org&journalCode=hlthaff.

[FN166]

“Palliative Care Programs Could Boost Hospitals' Bottom Line,” *U.S. News & World Report*, Sept. 12, 2008. 2008 WLNR 17362193.

[FN167]

Jane Gross, “Landscape Evolves for Assisted Suicide,” *The New York Times,* Nov. 11, 2008, at D8. 2008 WLNR 21519132.

[FN168]

“Palliative Care Research to Improve Care of Seriously Ill Patients to Benefit From $1.8 Million Award,” *Medical News TODAY*, June 4, 2010, available at: http://www.medicalnewstoday.com/articles/190816.php?nfid=60100.

[FN169]

Vida Foubister, “Case Study: Proving and Then Improving the Value of Palliative Care Services at Mount Sinai Medical Center,” reprinted by The Commonwealth Fund, Jan. 23, 2010, available at: http://www.commonwealthfund.org/Content/Innovations/Case-Studies/2009/Jan/Case-Study--Proving-and-Then-Improving-the-Value-of-Palliative-Care-Services-at-Mount-Sinai-Medical.aspx.

[FN170]

Kristen Gerencher, “CONSUMER HEALTH: Study Shows Benefits of Palliative Care,” *The Wall Street Journal*, Aug. 31, 2010, available at: http://online.wsj.com/article/BT-CO-20100831-708027.html.

[FN171]

Jenny Gold, Study: Suffering At The End Of Life Getting Worse, Not Better, Kaiser Health News (Feb. 3, 2015).

[FN172]

Genevieve N. Thompson, et al., “Pain Trajectories of Nursing Home Residents Nearing Death,” *The Journal of Post-Acute and Long-term Care Medicine* (Apr. 18, 2017), available at: http://www.jamda.com/article/S1525-8610(17)30134-2/fulltext.

[FN173]

Jim Parker, '53 Medicare Advantage Plans to Offer Hospice in 2021, Palliative Care to Grow,' *Hospice News* (Sept. 25, 2020), available at: https://hospicenews.com/2020/09/25/53-medicare-advantage-plans-to-offer-hospice-in-2021-palliative-care-to-growß°–/.

[FN174]

Nushin Rashidian and Alyson Martin, "Medical Marijuana Raises Tough Questions for Nursing Homes," *The New York Times*, Oct. 27, 2010, available at: http://newoldage.blogs.nytimes.com/2010/10/27/medical-marijuana-raises-tough-questions-in-nursing-homes/?src=mv.

[FN175]

Steven Nelson, 18 Congressmen Ask Obama to Reschedule Marijuana, *U.S. News & World Report* (Feb. 12, 2014), available at: http://www.usnews.com/news/articles/2014/02/12/18-congressmen-ask-obama-to-reschedule-marijuana.

[FN176]

"Internal Medicine Organization Issues Guidelines to Improve Care of 3 Symptoms at End of Life," *Drug Week*, Feb. 1, 2008. 2008 WLNR 1420102.

[FN177]

Clinical Practice Guidelines for Quality Palliative Care, 4th edition, National Coalition for Hospice and Palliative Care (2018), available at:

[FN178]

The full text of the guidelines is available at http://www.nationalconsensusproject.org/NCP_Clinical_Practice_Guidelines_3rd_Edition.pdf.

[FN179]

NAHC Releases Palliative Care White Paper (July 6, 2015) at: http://www.nahc.org/NAHCReport/nr150702_1/.

[FN180]

Jim Parker, "Lack of Palliative Care Definition Impacts Patients, Hospice Business," *Hospice News* (Nov. 2, 2019), available at: https://hospicenews.com/2019/11/01/lack-of-palliative-care-definition-impacts-patients-hospice-business/.

[FN181]

Peter May, et al., "Economics of Palliative Care for Hospitalized Adults With Serious Illness: A Meta-analysis," *JAMA Internal Medicine* (June 2018), available at: https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/2678833.

[FN182]

"Palliative Care in Florida: Challenges and Options for Florida's Future," *Florida TaxWatch* (Mar. 12, 2019), available at: https://floridataxwatch.org/Research/Full-Library/ArtMID/34407/ArticleID/18688/Palliative-Care-in-Florida-Challenges-and-Options-for-Floridas-Future.

[FN183]

Tanja Fusi-Schmidhauser, et al., 'Conservative Management of COVID-19 Patients?Emergency Palliative Care in Action*, Journal of Pain and Symptom Management* (Mar. 27, 2020), available at: https://www.jpsmjournal.com/article/S0885-3924(20)30183-4/pdf.

[FN184]

"A Comforting Swan Song?Palliative and Supportive Care," *Drug Week*, May 27, 2011. 2011 WLNR 10000117.

[FN185]

Gallagher, M., "Evaluating a protocol to train hospice staff in administering individualized music," *International Journal of Palliative Nursing*, 2011 Apr; 17(4): 195?201.

[FN186]

Robert Preidt, "?Palliative Care' Gets a Bad Rap, Study Finds," U.S. News & World Report?HealthDay (Apr. 19, 2016), available at: http://health.usnews.com/health-news/articles/2016-04-19/palliative-care-gets-a-bad-rap-study-finds.

[FN187]

Holly Gainer, “Study uses telehealth to provide palliative care to rural, Southeastern communities,” *UAG News* (Nov. 12, 2018), available at: https://www.uab.edu/news/health/item/9946-study-uses-telehealth-to-provide-palliative-care-to-rural-southeastern-communities.

[FN188]

ProCon.org provides an overview of the status of physician-assisted suicide laws and initiatives in each state and the District of Columbia.

[FN189]

O.R.S. ?? 127.800 et seq.

[FN190]

John Iwasaki, “State Second in Nation to Allow Lethal Prescriptions,” *Seattle Post-Intelligencer,* Nov. 5, 2008, at A15. 2008 WLNR 21175843.

[FN191]

William Yardley, “In Washington, First Death Using Assisted-Suicide Law,” *The New York Times*, May 22, 2009, at A10. 2009 WLNR 9828712.

[FN192]

Revised Code of Washington (RCW) 70.245.150.

[FN193]

The 2015 Death with Dignity Act Report is available on the Washington State Department of Health's website, at http://www.doh.wa.gov/portals/1/Documents/Pubs/422-109-DeathWithDignityAct2015.pdf.

[FN194]

Gonzales v. Oregon , 546 U.S. 243, 126 S.Ct. 904, 163 L.Ed.2d 748 (2006).

[FN195]

John Iwasaki, “Oregon Offers Lesson in Legal Assisted Suicide,” *Seattle Post-Intelligencer,* Oct. 16, 2008, available at: http://seattlepi.nwsource.com/local/383727_oregon17.html.

[FN196]

“PRESS RELEASE: 09.09.10 Study Finds Most Oregon Hospices do not Fully Participate in the Death with Dignity Act,” The Hastings Center, Sept. 9, 2010, available at: www.thehastingscenter.org/News/Detail.aspx?id=4868.

[FN197]

Sharon Bernstein, California governor signs bill legalizing physician-assisted suicide, Reuters (October 7, 2015).

[FN198]

Soumya Karlamangla, “Riverside Judge overturns California's doctor-assisted suicide law,” *Los Angeles Times* (May 15, 2018), available at: http://www.latimes.com/local/lanow/la-me-ln-end-of-life-option-act-20180515-story.html.

[FN199]

“D.C. Mayor Muriel Bowser Signs Death with Dignity Act of 2015,” Death with Dignity (Dec. 20, 2016), available at https://www.deathwithdignity.org/news/2016/12/dc-mayor-signs-death-with-dignity-act/.

[FN200]

Andrew Dugan, “In U.S., Support Up for Doctor-Assisted Suicide,” Gallup (May 27, 2015), available at http://www.gallup.com/poll/183425/support-doctor-assisted-suicide.aspx.

[FN201]

JoNel Aleccia, “Firing Doctor, Christian Hospital Sets Off National Challenge to Aid-In-Dying Laws,” *Kaiser Health News* (Aug. 30, 2019), available at: https://khn.org/news/doctor-fired-catholic-hospital-challenges-aid-in-dying-laws/.

[FN202]

Alanna Moriarty, “Top 10 Largest Health Systems in the U.S.,” *Definitive Healthcare* (blog, Aug. 1, 2018), available at: https://blog.definitivehc.com/top-10-largest-health-systems.

[FN203]

Final Conscience Regulation (Factsheet), Department of Health & Human Services (May 2, 2019), available at: https://www.hhs.gov/sites/default/files/final-conscience-rule-factsheet.pdf.

[FN204]

Neil M. Gorsuch, *The Future of Assisted Suicide and Euthanasia,* Princeton, N.J.: Princeton University Press, 2006.

[FN205]

Ben Tinker, “Physician-assisted suicide an issue for nominee Gorsuch,” *CNN* (Apr. 7, 2017), http://www.cnn.com/2017/04/06/health/gorsuch-assisted-suicide/.

[FN206]

“Palliative Sedation at End of Life is Appropriate in Cases of Extreme Suffering, Review Article Says,” McKnight's Long-Term Care News & Assisted Living, Oct. 4, 2010, available at: http://www.mcknights.com/palliative-sedation-at-end-of-life-is-appropriate-in-cases-of-extreme-suffering-review-article-says/article/180227/.

[FN207]

JoNel Aleccia, “At Some Veterans Homes, Aid-In-Dying is Not An Option,” *Kaiser Health News* (Feb. 13, 2018), available at: https://khn.org/news/california-joins-states-that-would-evict-veterans-who-seek-aid-in-dying-option/.

[FN208]

Lisa Rapaport, U.S. ‘right to try’ laws may not help dying get unapproved drugs, Reuters (Sept. 28, 2015).

[FN209]

HRSA, “State Organ Donation Legislation,” available at: https://www.organdonor.gov/legislation_micro/.

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