LeadingAge® Ohio

What the Media Said about End-of-Life Care This Week
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WITH DYING PATIENTS, FOCUS ON PATIENTS' GOALS IN CARE, BEING HONEST AND BEING GENTLE -– NOT SPECIFIC MEDICAL INTERVENTIONS: ENCOURAGE HOSPICE AND PALLIATIVE CARE

In "*The Magic Words: Turning Despair Into Hope,"* physician Ian Jenkins begins his thoughts on "how doctors should talk about the end of life" with their patients. In this article that appears in *Psychology Today,* Jenkins begin a series of articles that explore this topic. He opens by sharing the story of a 34-year-old patient who is dying from breast cancer, in spite of her endurance of multiple treatments. Jenkins arranged a meeting with himself, the oncologist and the patient. At the meeting, the oncologist said, "There's absolutely nothing we can do for you." Jenkins took over immediately, even as he could see the oncologist's unhappy reaction. He explained to the patient that what this means is there is no other chemotherapy option. But, he shared with the patient, we will continue to treat all symptoms, "'and we will *always* be with you and fight with you.'"

Jenkins point is that there are ways to "guide the patient to a gentle death." And ways to "convince a patient to enroll in hospice, ways that don't hurt." And, he stresses, there is always hope. He has seen physicians offer additional rounds of chemotherapy, even when they know it won't help.

The "magic first words," he says, is asking patients their understanding of their illness and options in care. Answers he has heard range from patients asking for hospice to patients asking for more treatment so they can get back to work.

In the second article of the series, Jenkins speaks of patient goals and "giving up." Often, patients are asked by healthcare professional providers, "Do you want CPR?" Jenkins says this question often offers the wrong choice. Simply, he says, don't offer inappropriate options. For example, Jenkins notes that "we don't ask dying people if they want open heart surgery because it would be nonbeneficial and harmful." CPR is often the same, he believes. So, he says, taking some options "off the table" helps to make end-of-life care conversations better.

Instead of asking about options in care, Jenkins says, seek goals in cares. Ask patients how they want to spend the time that remains in their lives, seek input on what brings meaning, and talk about hopes and fears. Jenkins says that no one has ever told him that they would like to "spend their last hour getting CPR in an ICU while on a breathing machine with no privacy and no proper family visitation." Instead, people almost always express their desire to be at home, with family and friends. And, says Jenkins, medical professionals can help this to happen. Talk about hospice "(generally speaking, no more invasive procedures, with exceptions, avoid hospitalization, manage symptoms instead of actively fighting the underlying process, focus on comfort. . .)"

Simply put, listen to and set patient goals, and focus on what is important. Some patients identify themselves as fighters and want every intervention possible. Tell these patients, Jenkins advises, to consider the results of such decisions. Jenkins tells these patients, "If you get intubated, you will lose the chance to die peacefully at home. You have to give up talking with loved ones. . ." Then share the advantages of hospice. He says, "Enrolling in hospice will mean more specialists devoted to managing your symptoms, You'll gain more control about how you send your time. . ." In doing this, Jenkins says, we "make it easier for fighters to fight…a different way."

Still, some patients will interpret the ceasing of active treatment as surrender. And it isn't wrong that these fighters want the next treatment. When dying becomes "unavoidable," he tells fighters things like, "I know you want to do everything you can to fight your illness. They've done research to see what the effect of palliative care is for cancer patients like you." He tells them that palliative care helps patients live longer and better. It reduces pain and suffering. It lessens stresses such as going out for appoints. So, he tells his patients, he worries that they will miss out on a longer life by avoiding palliative care. "You're a fighter—let's fight this with every tool we have." Not only is helpful to say these things to patients, Jenkins says, it is true. Palliative care itself offers a way of fighting.

He ends by noting that if he changes these messages to tell patients that they need to make these choices, they can just disagree with him. But if he shares that he is worried about the outcomes of some treatment choices, patients don't argue because he is expressing his own view and concern.

In part 3 of the series, "The Magic Words: Tips for Gentle Honesty," Jenkins first word of advice for sharing bad news is: sit. When there will be talk about end of life, we need to make it clear we will "devote some time to the issue." Choose a time that works for the patient, have them invite key family and friends, anticipate the questions, and be really present. Be honest, but don't be brutal. This breaking of bad news is a "process, not a single event." Jenkins spends time in the article to share how this process might unfold. Being honest and truthful is appreciated by patients.

The series will continue, and a link to each of these three articles is below. (*Psychology Today,* 2/14) ***Read Part 1: The Magic Words: Turning Despair Into Hope***; (*Psychology Today,* 2/14) ***Read Part 2: The Magic Words: Goals and Giving***; (*Psychology Today,* 2/15) ***Read Part 3: The Magic Words: Tips for Gentle Honesty***

AARP CALLS FOR PERMANENT EFFORTS TO SUPPORT AND EMPLOY FAMILY CAREGIVERS

Before the pandemic, 33 states had caregiving options for self-directed long-term services and supports(LTSS). Since the beginning of the pandemic, 15 more states have expanded their LTSS programs “to allow hiring of family members.” *AARP* released a report “LTSS Choices: Paying Family Caregivers to Provide Care During the Pandemic-and Beyond.” The report supports the permanent practice of paying family caregivers, and call it “‘a solution that saves states money and meets the growing need for long-term care.’”

From an economic perspective, “the value of unpaid family caregiving was estimated at approximately $470 billion in of [sic] 2017, and this number will only increase as more Americans than ever are turning 65 and older.” For America’s healthcare policy to allow compensation for these caregivers, there will need to be significant changes. *AARP’s* report focuses on paid family caregiving. In so doing, it also analyses the current programs and funding sources.

A significant overview of the challenges of long-term care, and the needs of those who are aging and need care, is provided. The shortages of direct care staff are noted. The needs of the frail and aging are underscored. The report notes the concerns about paying family caregivers, but says that research demonstrates “that fraud is extremely rare.” And the practice of paying family caregivers has been an ongoing one, that has seen even more of the shift because of the pandemic. And it is not clear whether paying family caregivers will become part of a systemic change.

AARP notes the benefits that come from the practice of paying family caregivers for those in serious need of this help. It expands the number of caregivers who are available as the need for such caregivers grows. It benefits patients, caregivers, and the entire family. Also, says the report, “Expanded access to HCBS is a successful outcome both for people who need LTSS and for taxpayers.” And it supports the vast majority of these patients who want to remain at home. Caregiving needs are often at a level high enough to make it impossible for caregivers to hold another job, and payment for their services is important.

Economically, one analysis shows that Medicaid-funded self-direction programs offer a monthly budget of $1,774 for this care in 2019. Medicaid-funded care for nursing home, in a semi-private room, was $6,175 per month. *AARP* calls on states’ Medicaid agencies to “consider implementing permanent policies that encourage and facilitate paid family caregiving.” To do this, the report encourages “easing restrictions on the types of family members who can provide paid service via Medicaid-funded self-direction programs. Raising the Medicaid budget to support more professional caregivers is a difficult task. But allowing better access to family caregivers is “cost-effective and safe.” (*AARP,* 2021) ***Read the report here***.; (*McKnight’s Senior Living,* 2/5) ***Read more...***

HOSPICE NOTES

* *Humana* is a part of CMS's four-year demonstration project "of a Medicare Advantage (MA) value-based care model for hospice patients, which aims to improve care coordination." The demonstration allows patients and families to transfer to hospice and remain with the same healthcare team. Humana **created a webpage** to explain to health care providers about the pilot. If CMS approves, more demonstrations will begin in 2022. (*HealthPayerIntelligence*, 2/11) ***Learn more...***

* *National Partnership for Healthcare and Hospice Innovation (NPHI)* shared about a private meeting of the group members' CEOS "to highlight the Biden administration's key healthcare policy priorities." Tom Koutsoumpas, CEO of *NPHI,* said, "We must make sure that the future of care our members are providing isn't diluted by those getting into hospice care simply for profit, which is happening all too often" (*NPHI,* 2/10, ***Read more...***

PALLIATIVE CARE NOTES

* A recent study published in *Palliative Medicine Reports* says that patients who receive palliative care when they are inpatients "were significantly more likely to receive home-based palliative care after discharge." The researchers say that "inpatient palliative care offers a distinct opportunity to improve transitional care between hospital and home. . ." (*Palliative Medicine Reports,* 2/3) ***Read more...***

* Palliative care and family medicine physician Dr. Shireen Heidar pinned *"Touch and the absence of it,"* an essay published in *The Lancet.* She tells the story of asking a patient how she knew when she was dying. The patient answered that her physician used to check her heart and lungs at each visit, and now no longer does this. Heidar's essay focuses on the meaning of touch and the loss of touch that has been created during the pandemic. An article in *The Stanford Daily,* where Heidar practices, features an interview with Heidar. In her practices, she focuses on what brings joy and meaning to her patients, "making each day as good as possible." (*The Lancet,* 1/22) ***Read more...*** (*The Stanford Daily,* 2/8) ***Read more...***

* Globally, the palliative care market will burgeon to reach $6.10 billion by 2027. An analysis by *Reports and Data* forecasts that the palliative care market, which "held a market share of USD $2.95 billion in the year 2018," will grow at a rate of 8% during the next six years. The report also says that hospice residential care will see the fastest rate of growth, with 11.3%. (*Reports and Data,* 2/4) ***Read more...***

END-OF-LIFE NOTES

* *Santa Fe New Mexican* supports House Bill 47 that will allow terminally ill New Mexicans to engage in a process to seek assistance in getting medications to help them die. The bill has already passed the Health and Human Services Committee and is awaiting a hearing with the House Judiciary Committee.
(*Santa Fe New Mexican,* 2/10, ***Read more...***

* Those who supported physician-assisted suicide in California promised that no physician would be required to participate in the practice, says an article in *National Review.* A bill, SB 380, has now been filed and would require physicians to help patients find another prescriber who will help if they are not willing to do so themselves. (*National Review,* 2/11) ***Read more...***

* *Compassion and Choices* praises California's SB 380 that will prevent the current End of Life Option Act from expiring in a few years. The bill would simplify the current process to increase access and to help consumers receive the care they choose. A study by *Kaiser Permanente Southern California,* available at the second link below, reveals that the process is time consuming and that a third of those who requested to use the act died before the 15-day waiting period. (*Compassion and Choices,* 2/11) ***Read more...*** (*JAMA,* March 2018) ***Read more...***

* An article in *Las Cruces Sun News* explores the views of New Mexican's as the state considers HB 47 that would legalize the practice of physicians to prescribe medications to help terminally-ill patients to end their lives. The article shares the views of the Archbishop of Santa Fe, a hospice medical director, a hospice social worker, a disabilities advocate, a state representative, and a family member of a now deceased patient. (*Las Cruces Sun News,* 2/11) ***Read more...***

* "Hospitals resist Our Care, Our Choice Act," reads the headline in *Hawaii Tribune-Herald.* The aid-in-dying laws, passed in 2019 in Hawaii, are hard to access for some Hawaii residents * * Some Hawaiian residents face barriers when trying to access care under the OCOCA act because of lack of participation by providers. "The East Hawaii Region of the Hawaii Health Systems Corp., which includes Hilo Medical Center, will not participate in OCOCA-related services on its premises, according to a new policy implemented this month." This means that patients diagnosed with a terminal illness may, if they request, receive support and referrals to others who do provide access to care in the East Hawaii Region facility. Hospital CMO Kathleen Katt voices appreciation that the people of Hawaii are "allowed this service," but says that the hospital doesn't "have the resources that are needed to be able to fulfill all of the requirements." The same stance is true for Queen's North Hawaii Community Hospital in Waimea. And Kona Community Hospital is working to adopt an "'engaged neutrality'" position that will provide consumer education to help citizens be informed, but will not allow "the administration of end-of-life medications" on the campus. Advocates for end-of-life rights say, this lack of access to providers provides a significant barrier for patients. And, in East Hawaii, access is especially difficult. (*Hawaii Tribune Herald,* 2/14) ***Read more...***

ADVANCE CARE PLANNING NOTE

* An article in *Scientific American* encourages conversation about the "deeper society questions about who gets the privilege to plan" for end-of-life care. The author, a medical anthropologist and professor of social medicine, notes that death often pays no attention to our plans. Advance care planning has become even more important during the pandemic. But when it comes to engagement in advance care planning, Americans are not equitably engaged. As she elaborates on this inequity, and encourage conversations about end-of-life care, she says, "Let's make sure that a piece of this conversation is facing the tough questions about who among us will get to plan and choose" (*Scientific American,* 2/10) ***Read more...***

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