What the Media Said about End-of-Life Care This Week
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CONSUMERS SAY HOSPICE COMMUNICATION WITH PATIENTS AND FAMILIES NEEDS IMPROVEMENT

A recent survey of 300 family caregivers of hospice patients revealed that hospice communications are not meeting the needs of many caregivers. Only 43% of the family caregivers reported that they were "very satisfied" with the hospice providers in the areas of: "(1) communication with family, (2) training family to care for the patient, (3) getting timely help, and (4) emotional and spiritual support."

The survey, conducted by Citrus Health and Porter Research, reveals that "90% of family caregivers indicate that the method of communication that hospices use influenced their overall satisfaction scores." Low satisfactory scores come when immediate responses from hospice providers are not forthcoming, when phone tag is required, and when repeated calls are needed in order to get a response. Those who received timely communications reported higher satisfaction.

The survey reports that hospices tend to use "outdated communication methods." Use of phones, texts, and emails all have some limitations, says the research, and better options are available for use. Findings of this survey should increase interest in using these better options. **"Secure, real-time group messaging solutions that include the care team, family caregiver and external partners" are available.** This issue of communication is very important, because 78% of caregivers report that they "would choose a hospice that enables instant communication through computer, tablet, mobile." And "80% of family caregivers would give hospices that provide instant communication" higher scores.

The message is clear: Hospices that want to better serve patients and families must make improved communications a priority and invest in technology to do so. This seems to match hospices' hopes as well, because only 26% report that they are satisfied with their current level of investment in technology. Though many hospices have invested in upgraded technology to improved record keeping, the investment is not improving relationships with family caregivers.

"New Consumer Research Reveals Hospice Communication Strategies Lag Consumer Expectations," appears in *NHPCO's Summer Newsline.* The article shares the results of the survey and a roadmap to lead to improvement in family communications. Recommendations are given for important steps that can be enhanced via improved communications and technologies. Suggestions include that hospices provide families with an immediate response to urgent or emergency questions. Offer opportunities for families to speak directly, via video, with the medical director. Facilitate group chats with the hospice nurse and the entire family. "Coordinate medication and equipment needs." Inform families about changes in planned visit times by hospice staff.

Overall, the message is clear: "Realtime communication technology is now a 'must have.'" The investment in doing this will strengthen productivity, better meet family needs, and "allow more time for clinical staff to care for patients." (*NHPCO Summer Newsline,* Summer 2021)

COLORADO SETS CRISIS STANDARDS FOR HOSPICE AND PALLIATIVE CARE – ENCOURAGES OTHER STATES TO DO LIKEWISE

"Palliative care (PC) and hospice services have experienced shortages before 2020, and during the initial

phases of the current pandemic, more critical gaps are expected with future surges, much as scarcity in intensive care unit services may recur during the COVID-19 pandemic." That is the first sentence in "Colorado Palliative Care and Hospice Crisis Standards: Moving Beyond Critical Care Planning," which appears in *Journal of Pain and Symptom Management*. With current shortages, and future "surges" of crisis need for care in mind, the authors share about their work to look at gaps of care within the state. The article "describes the planning initiatives Colorado has developed to address potential scarcities for this vulnerable and diverse groups of people." Authors also hope that, by sharing their work, other states might consider these needs and plan for the future.

Near the beginning of the pandemic, in March 2020, a number of hospital stakeholders created an ad hoc "virtual ethics meeting" to address concerns related to ventilators and ICU beds in order to create fairness, consistency, and sharing of resources in all Colorado hospitals. Before the group convened, they shared their concerns with the Colorado Department of Public Health. (CDPH). CDPH and several ethicists and other clinicians joined the group. By the next month, the working group grew to "135 people from 45 institutions and organizations and 16 cities in Colorado."

The group reviewed earlier plans, determined their hospice and palliative medicine (HPM) goals, identified the gaps, and created a crisis action plan. In the group's formation, there was a clear concern about gaps that result in a lack of adequate hospice and palliative care (PC) staff across systems—hospitals, facilities, community provider organizations and hospices. The group worked to address gaps by designating "palliative care specialists;" developing a 24/7 virtual system for providers to support HPM wherever needed; providing a communications infrastructure; and assuring "liability protection for provider-to-provider consultation."

Another gap identified issues with "stuff." The group anticipated shortages in pain management medication. The action plan focused on maintaining an ongoing inventory; requiring sharing as necessary; and updating regulations allowing scheduled drugs to be given at "overflow sites."

Other gaps identified, and plans of action created, revolved around equipment shortages, PPE shortages, lack of adequate testing, lack of equipment to support virtual communications, space for all very ill patients, regulatory barriers related to advance directives, inadequate emotional and psychosocial support, and isolation and loneliness. The Colorado crisis standards were approved in June 2020. As the pandemic continues, several areas have been the focus of concern.. The first is that "goals-of-care conversations must use the best evidence available." Secondly, "excess deaths need to be better understood." Thirdly, "disparities in access to support PC and hospice workers are being highlighted and exacerbated by the pandemic."

The article concludes by noting the clear reality that "the COVID-19 pandemic has strained communities, elected leaders, patients, and clinicians." Gaps in care have become clearer, and difficulties in receiving quality care have increased for those living with acute, chronic and life-limiting illnesses. Community anticipation of needs will help reduce overall stress.

Too few states have worked to create crisis plans, say the authors of the article, who hope their sharing will encourage other states to do so. Lack of crisis planning, they say, creates outcomes that leave "decisions to the local level and risking inequity and even rationing, as well as missing a chance to address suffering across the healthcare system. A link to the abstract of the article is posted below. (*Journal of Pain and Symptom Management*, June 2021, https://www.jpsmjournal.com/article/S0885-3924(20)30936-2/fulltext)

HOSPICE NOTES

*** "Hospice and palliative care falling short in Black community" appears in *McKnight's Senior Living.*** The article highlights the work of *NHPCO* in creation of "Black and African-American Outreach Guide." The guide urges hospice and palliative care providers to partner with faith-based groups and get involved in community events. Alliances and partnerships are key to outreach. Hiring staff from the African-American community is also important. *NHPCO* is also working to address needs of other underserved communities. Similar guides will come soon of meeting needs of "Chinese American, Latinx and LGBTQ communities. (*McKnight's Senior Living*, 6/7, https://www.mcknightsseniorliving.com/home/news/home-care-daily-news/hospice-and-palliative-care-falling-short-in-black-community/)

* ***Solace Friends*, in Madison, Wisconsin, is a new nonprofit focused on offering hospice to homeless people near life's end.** Slated to open in 2022, the hospice house will serve vulnerable people and offer hospice care "to target people who just fall through the cracks or don't have any other options." *Solace Friends* wants to offer "'exquisite kindness' and welcome for people who maybe haven't been welcomed other places." (*Wisconsin Public Radio,* 6/17, https://www.wpr.org/comforting-end-nonprofit-aims-create-hospice-house-those-experiencing-homelessness?fbclid=IwAR34dhzWGNMGW6rlu8QsUvJOhfBRPSW2GNsYsXeLO3fChKcpNWJQGBNbWQ4)

* ***NHPCO* launched a "new and expanded Caringinfo.org website."** This consumer-oriented site provides information "on hospice, palliative care, grief and bereavement, caregiving, planning ahead, and more." The website now features easier navigation and enhanced resources. (*EINPRESSWIRE*, 6/17, https://www.einnews.com/pr_news/544009778/nhpco-launches-re-envisioned-caringinfo-org-consumer-website)

* **Perceptions of hospice staff and acupuncturists in Oregon were explored in a statewide survey.** Ninety-one percent of surveyed acupuncturists and sixty-nine percent of hospice staff agreed that "acupuncture can help provide a higher quality of life for hospice patients." Responses indicate that several factors keep the use of acupuncture low among hospice patients. These include perceptions of insufficient evidence of the value of acupuncture, and not enough sources of financial coverage for the service. (*Physicians Weekly,* 6/17, https://www.physiciansweekly.com/perceptions-that-influence-acupuncture-use-in-hospice-settings-results-of-a-state-wide-survey-study)

* **"Pet Peace of Mind" works to help patients care for their pets and "alleviate worries about their pets' welfare and future."** Ohio's *Western Reserve Hospice* has introduced the program in their hospice. Executive Vice Present and COO John Mastrojohn shares about the program in an article in Ohio's *News-Herald.* The volunteer-lead program assists owners of dogs and cats. Details of the program, and the range of services, are provided in the article. (*News-Herald,* 6/16, https://www.news-herald.com/news/cuyahoga-county/hospice-of-the-western-reserve-program-aimed-at-keeping-patients-united-with-pets/article_adab48a8-cd2d-11eb-b74b-e3f18a8c96b2.html)

* ***Wellsky* is "a technology company advancing human wellness worldwide" The** company offers a cost-free webinar on the 2022 CMS-proposed rule on regulatory and quality reporting changes for hospice. To view the online webinar, registration is required. Registration and more details about the webinar are available at the link below. (*Wellsky,* https://info.wellsky.com/2022_hospice_proposed_rule.html)

PALLIATIVE CARE AND END-OF-LIFE NOTES

*** New York's *Feinstein Institutes for Medical Research* has been granted over $1.6 million to "support a trial to expand the use of video, educational materials and a palliative care educator specialist for optimizing patient-centered goals of care planning."** The award is from the *National Institutes of Health (NIH) National Institute on Aging (NIA).* Details of the plans and potential partners are online at the link below. (*businesswire,* 6/18, https://www.businesswire.com/news/home/20210618005338/en/Feinstein-Institutes-gets-1.6M-from-NIH-to-study-video-palliative-care-services)

* **Virginia Chang, Ph.D., is an end-of-life doula and author of an opinion piece in *Scientific American.*** In "How End-of-Life Doulas Help Ease the Final Transition," Chang offers several examples of how doulas act as an "advocate, cheerleader, companion, guide, ear, rock" for patients as they reach the end of their lives. She also notes that 60.5 percent of deaths happened in hospitals in 1980. By 2016, that number was cut in half, with 29.5% dying in hospitals and 30.5% dying at home. But, she notes, 71% say they want to die at home. (*Scientific American,* 6/19, https://www.scientificamerican.com/article/how-end-of-life-doulas-help-ease-the-final-transition/)

*** *End of Life University* features Judy Hilyard, a long-term ICU nurse who "now serves as an Anam Cara, or 'soul friend' to the dying.** She shares her understanding of spiritual issues of the dying, and how she came to this work. The audio is online at the link below. (*End of Life University*, 6/14, https://eolupodcast.com/2021/06/14/ep-303-anam-cara-soul-companion-for-the-dying-with-judy-hilyard/?mc_cid=2b480f6321&mc_eid=d0771da91c)

* ***Rolling Stone* has an article titled, "Can Psychedelics Help Make Dying Easier?"** The article shares about the growing body of knowledge that points to the value of psychedelics for terminally ill, about terminal patients who

want to access the drug to help with their suffering, and the legal situation that centers around Washington's "Right to Try law," the illegality of psilocybin, and the evolution of the status of psylocibin. Kathryn Tucker, an attorney focused on easing suffering for dying patients, is one of seven attorneys working with Dr. Sunil Aggarwal and his *AIMS Institute* in suing the Department of Justice (DOJ) and DEA for the barriers they raise to prevent patient access to the drug. On 6/21, says the article, DOJ will file a brief on behalf of the DEA. On July 12, Aggarwall and patients, the petitioners, will reply. Then, likely in September, the oral argument will occur. (*Rolling Stone*, 6/17, https://www.rollingstone.com/culture/culture-features/psychedelics-death-anxiety-psilocybin-1184240/)

GRIEF AND ADVANCE CARE PLANNING NOTES

*** "Discussing End-of-Life Care May Boost Hope for People With Advanced Cancer," appears in *Cancer Health.*** Advance care planning does not minimize hope or optimism in people with cancer, finds a survey presented at the *American Society of Clinical Oncology*. "In fact," says the article, "they may become more hopeful." Providers are sometimes reluctant to start the conversation because they worry about patient responses. But the study shows that the end-of-life planning does not lead to less hope. (*Cancer Health*, 6/14, https://www.cancerhealth.com/article/discussing-endoflife-care-may-boost-hope-people-advanced-cancer)

*** David Kessler is author of *"Finding Meaning: The Sixth Stage of Grief."*** What held significant meaning in our lives changes when someone we love dies. When experiencing this grief, he advises, making "extreme alterations" is not advised. "Grief can also cloud your reasoning," he says. Finding meaning does not come in the event of death of loved ones. "Meaning is in us afterward." (*Fast Company*, 6/11, https://www.fastcompany.com/90645579/post-pandemic-life-6th-stage-of-grief)

* **In a review of 423 outpatient encounters between cancer patients and oncologists, only 5% of the visits included a discussion of EOL care.** Too often, the oncologists missed opportunities by inadequately responding to patients concerns. The authors of the article in *JAMA Network Open* calls for improving "sensitivity to EOL discussions, to avoid unnecessary EOL treatment." These discussions could improve patient EOL care. (*JAMA Network Open*, 6/10, https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2780865)

*** *Oregon POLST Program* and the *Oregon POLST Registry* are hosting a free webinar. The webinar is titled "New Innovations: The New Oregon POLST Registry Platform Expands Access and Informs Quality Improvement."** The webinar will take place on July 14 at noon PT. Registration is required and is available at the link below. (*Oregon POLST*, https://oregonpolst.org/webinar-registration-form)

OTHER NOTES

*** Amazon has a program for hospitals that predicts patient mortality.** *Amazon Healthlake* launched in December and now holds data of over 40,000 patients who have had stays in critical care units. The data contains numerous demographics on the patients. Healthcare providers "can use the data to spot trends and find anomalies to make predictions about the progression of disease, clinical trial efficacy and accuracy of insurance premiums." *Healthlake* can produce "outcome predictions, such as mortality rates, acute or chronic condition-triggered hospital visits or hospice readmission." The hope is that "providers, payers and pharmaceutical companies can predict results and recommend early intervention, improve outreach to patients and reduce costs." (*Becker's Hospital Review*, 6/11, https://www.beckershospitalreview.com/data-analytics/amazon-s-healthlake-can-predict-patient-mortality-4-details.html)

* An **article in *People* examines the growing interest in human composting.** *Recompose*, a nonprofit organization, founder Katrina Spade is featured as the originator of the idea. *Recompose* is the “country’s first funeral home to offer human composting.” The Seattle-based company, opened December 20, 2020, and has composted 50 bodies, is working on 25 more, and have 775 signed up in the pre-pay membership. Washington is the first state to legalize the practice. Colorado and Oregon legalized the practice this spring. New York and California are looking at legalizing the practice as well. (*People*, 6/17, https://people.com/human-interest/human-composting-a-new-end-of-life-choice-turns-bodies-into-soil/)

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