



## What the Media Said about End-of-Life Care This Week June 15, 2021 A Service of Your State Association

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### **STUDY REVEALS BEREAVED FAMILIES ARE MORE LIKELY TO SAY LOVED ONES RECEIVED “TOO LITTLE” CARE RATHER THAN “TOO MUCH” CARE AT LIFE’S END**

**There are sometimes concerns about patients receiving too much aggressive medical care as they are dying.** A study in *Journal of Palliative Care* focused on examining next-of-kin perceptions about the medical care received at life’s end. The study was a survey focused on adults (18 years and older) and on nontraumatic deaths. The focus question given to the 623 survey participants was: “During the last month of your family member's life, did he or she receive too little, the right amount, or too much medical care?” Eighteen measures of quality care were also examined.

**Of all the survey respondents, “16.9% reported their loved one received ‘too little’ care, while only 1.4% reported ‘too much.’”** While the concerns expressed include physician communication, and adequate palliation, **“the predominant concern was inadequate symptom management.”** Overall, though the majority of respondents felt the amount of care received was the right amount, the notable minority (one in six) felt the care received was too little.

There are some difference in respondent concerns related to cause of death and respondent’s education. But, **“There were no differences by age, gender, site of death, insurance type, or by functional trajectory in the last year of life with the perception of receiving too little care in the last month of life.”**

**Author Joan Teno, et al, offer comprehensive reporting on details of the input by the survey participants.** In the conclusion of the article, a 2004 *JAMA* article, calling for improved end-of-life care, is cited. The realities calling for improvements in 2004 remain true today.

In response to the article, a letter to the editor says, **“We would argue that care is not synonymous with clinical treatment or intervention.”** The authors express concern about numerous findings and conclusions of the study. In conclusion, they say, **“We would argue that the study’s findings have greater currency in highlighting where improvements are needed across all settings of care than they do in the unrelated debate around nonbeneficial interventions.”**

The authors of the original article respond, **“Key to examining quality of care is understanding persons’ and their close family members’ perceptions of the medical care received.** Those perceptions may be clinically incorrect, but they remain important.” **The perceptions and stories of survivors were the focus of the survey, and not the concerns of the experts.** “It was disheartening,” they say, to find “the same concerns and suffering of bereaved family members” as those expressed in the 1995 *SUPPORT* study. **“We must do better.”**

(*Journal of Palliative Medicine*, June 2021, <https://www.liebertpub.com/doi/10.1089/jpm.2020.0498>;  
<https://www.liebertpub.com/doi/10.1089/jpm.2021.0074>; <https://www.liebertpub.com/doi/10.1089/jpm.2021.0156>

### **HOSPICE NOTES**

**\* In response to the “Hospice Wage Index Proposed Rule,” NHPCO submitted comments to the administrator of *The Centers for Medicare and Medicaid Services*.** The lengthy response is detailed and prescriptive in terms of recommendations. *NHPCO’s* comments focus “on the potential impact of these proposals on hospice providers serving patients with serious and life-limiting illness and their families.” The response is online at

the link below. (NHPCO, 6/7, <https://www.nhpco.org/wp-content/uploads/NHPCOCommentsFY2022HospiceProposedRule.pdf>)

\* **OIG issued “Medicare Hospice Provider Compliance Audit: Professional Healthcare at Home, LLC.”** The publication says, “Previous *OIG* audits and evaluations found that Medicare inappropriately paid for hospice services that did not meet certain Medicare requirements.” This audit was to see if *Professional Healthcare at Home, LLC*, complied with the requirements of Medicare. Of 100 claims examined by *OIG*, they deemed that, for 21 claims, “the clinical record did not support the beneficiary’s terminal prognosis.” Based on this and other findings, *OIG* estimated that the company received “at least \$3.3 million in unallowable Medicare reimbursement for hospice services.” *Professional Healthcare* disputes nearly all findings, but *OIG* disagrees. The second link below leads to the “Report in Brief.” (*OIG*, 6/10, <https://www.oig.hhs.gov/oas/reports/region9/91803028.asp>; *OIG*, June 2021, <https://www.oig.hhs.gov/oas/reports/region9/91803028RIB.pdf>)

\* **“HHS stepping up enforcement of patient rights, lawyer cautions” is an article in *McKnight’s Senior Living*.** An attorney speaking at a *NAHC* webinar alerted providers that, “Home care and hospice providers received a warning” that HHS “is cracking down on rules covering patient privacy and access to health records.” Attorney Madison Pool says HHS “has been stepping up enforcement of patient rights.” Pool also advised “home care and hospice agencies to conduct risk assessments and put in safeguards to ensure persona health records (PHI) can be transferred safely across various platforms. (*McKnight’s Senior Living*, 6/10 <https://www.mcknightsseniorliving.com/home/news/home-care-daily-news/hhs-stepping-up-enforcement-of-patient-rights-lawyer-cautions/>)

\* **North Carolina’s Burke Hospice and Caldwell Hospice are merging.** The two hospices will be named Amoren, Latin for love. Both Burke and Caldwell are community-owned providers. Full integration will occur over the next 12 to 18 months. (*Caldwell Hospice*, May 2021, <https://www.caldwellhospice.org/about/news>; *Burke Hospice*, June 1, <https://www.burkehospice.org/news/2021/6/1/burke-hospice-amp-palliative-care-and-caldwell-hospice-and-palliative-care-officially-integrated-to-become-one-provider>) <https://www.burkehospice.org/news/2021/6/1/burke-hospice-amp-palliative-care-and-caldwell-hospice-and-palliative-care-officially-integrated-to-become-one-provider>)

\* **Attorney Meg Pekarske, whose practice serves legal needs of hospices, visits with Dr. Kathleen Benton of Hospice Savannah.** Benton shares how the hospice works to meet community needs and expand services and partnership. The *Hospice Insight* discussion is available in audio format at the link below. (*Husch Blackwell*, 6/2 <https://www.huschblackwell.com/newsandinsights/hospice-innovators-a-conversation-with-kathleen-benton-ceo-of-hospice-savannah>)

## PALLIATIVE CARE NOTES

\* **As Medicare Care Choices Model is concluding, CMS says it will likely be starting a palliative care payment option.** Chris Smith Ridder, Ph.D., is director of the *Patient Care Models Group for CMS’s Center for Medicare and Medicaid Innovation (CMMI)*. Ritter spoke at a *LeadingAge* summit. During her presentation, “Ritter indicated that *CMMI* is interested in moving away from fee-for-service and toward more capitated payment models.” (*McKnight’s Senior Living*, 6/10, <https://www.mcknightsseniorliving.com/home/news/home-care-daily-news/cms-innovation-arm-signals-it-is-moving-toward-palliative-care-capitation-payment-models/>)

\* **A recent study found that knowledge of palliative care is low.** Of 3,450 people surveyed, 89% had “inadequate knowledge of palliative care.” The study calls for improved public health education. Also, the article says, “Healthcare providers have a major role to play in improving palliative care knowledge. (*Cancer Epidemiol Biomarkers Prevention*, 6/4, <https://cebp.aacrjournals.org/content/early/2021/06/01/1055-9965.EPI-20-1790>)

\* **An article in *Oncology Nursing News* reports on a study that reveals that nurses are often “begging for palliative care specialists” to see patients, but find that attending physicians often feel no need for this.** Integrative palliative care, says the article, leads to a better quality of life for patients living with acute myeloid leukemia (AIM) who are receiving “intensive induction chemotherapy.” Nurses see first-hand the need for palliative care, and they serve as advocates for these patients. (*Oncology Nursing News*, 6/9, <https://www.oncnursingnews.com/view/nurses-have-the-responsibility-to-be-the-voice-of-the-patient-in-palliative->

care-advocacy)

<https://www.medicalbag.com/home/news/benefits-early-palliative-care-chronic-disease/>

## END-OF-LIFE NOTES

**\* Several years ago, grief therapist Kelly Grosklags pulled back from her private practice in order to focus more on teaching and writing.** When one of her last patients, Judy Erdahl, asked what Grosklags was going to do, Grosklags shared that she hoped to make an education film to help medical professionals “have difficult end-of-life conversations.” Erdahl, near the end of her own life, said she wanted to be in the film, and do so as a part of her legacy. Grosklags teamed with a former news anchor, and together they created a 35-minute documentary, “Dying Is Not Giving Up.” The film focuses on healing during the last months of life. The film will be shown at no cost in a virtual viewing on June 16. The second link below has the registration site. (*Star Tribune*, 6/11, <https://www.startribune.com/duo-teams-up-to-give-patients-time-tools-and-tenderness-to-talk-about-death/600067336/>; *EventBrite*, <https://www.eventbrite.com/e/dying-is-not-giving-up-tickets-153684316929> )

**\* “Prognosis: notes on living” is a film with Debra Chasnoff who is “diagnosed with stage-4 breast cancer and faces down injustice as always, with her camera.”** An Oscar winning filmmaker of documentaries, Chasnoff “traces the journey through the twists and turns of living with cancer.” The world premiere of the movie streams on 6/19, with a second option on 6/26. Tickets, at no cost, are available online at the second link below. The home page of the film and a trailer at available at the first link. Chasnoff’s journey is “a story about holding onto people we love, as we prepare to get go.” (*Groundspark*, <https://groundspark.org/prognosis-notes-on-living>; *Frameline45*, <https://www.frameline.org/festival/film-guide/prognosis-notes-on-living>)

**\* *The Chinese American Coalition for Compassionate Care (CACCC)* works with several partners serving California’s bay area Chinese. The group focuses on assuring that Chinese residents receive appropriate information and support in facing life’s end with dignity and respect.** The group provides, in Chinese, “advance care planning; palliative care and hospice care education, caregiver and volunteer training, community education and outreach, and professional healthcare forums.” The organization recently received a \$10,000 unrestricted gift from Stupski Foundation. (*Mercury News*, 6/13, <https://www.mercurynews.com/2021/06/13/grant-will-aid-end-of-life-care-for-local-chinese-americans/>)

## GRIEF AND ADVANCE CARE PLANNING NOTE

**\* *Center for Loss and Life Transition* posts “Helping Yourself Heal When Someone Dies.”** The video presentation by Dr. Alan D. Wolfelt is available online. (*Center for Loss and Life Transition*, 6/8, [https://www.youtube.com/watch?v=eHS0yF2EFLY&ab\\_channel=CenterforLoss%26LifeTransition](https://www.youtube.com/watch?v=eHS0yF2EFLY&ab_channel=CenterforLoss%26LifeTransition))

*Hospice Analytics is the national sponsor of Hospice News Network for 2021. Hospice Analytics is an information-sharing research organization whose mission is to improve hospice utilization and access to quality end-of-life care. For additional information, please call Dr. Cordt Kassner, CEO, at 719-209-1237 or see [www.HospiceAnalytics.com](http://www.HospiceAnalytics.com).*

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