



What the Media Said about End-of-Life Care This Week May 17, 2022 A Service of Your State Association

BLACK LEADERS CONSIDER RACIAL DISPARITIES IN END-OF-LIFE CARE AND ADVANCE CARE PLANNING

Two African American leaders in end-of-life care, Dr. D. Dennis Cross, MD, and Dr. Gloria Thomas Anderson, PhD, LMSW, have been the focus of recent media. While millions of persons and families choose hospice care, many fewer people of color make the same choice. In Minnesota, D. Dennis Cross addresses racial disparities in hospice, and is working to help more people of color experience “the comfort of hospice.” An article in Minnesota’s *Star Tribune* features an interview with Cross to explore why these racial disparities continue to exist.

Cross serves as a hospice physician to hospice patients and their families of Our Lady of Peace in St Paul. The article cites the Minnesota Network of Hospice and Palliative care as saying, “53% of Minnesota white patients used Medicare hospice benefits at the end of life compared to 38% of patients of color. That Minnesota gap is slightly larger than on the national level.” And Black patients sometimes suffer from not receiving hospice. One example is noted in a recent study by Duke University. They found, “Black Americans are more likely to experience untreated pain at the end of life because of the disparity in using hospice.”

One factor that impacts reluctance to enroll in hospice, says Cross, is the practice of Black families taking care of our own loved ones. Also, African Americans have a deep history of distrust of medical providers because of the ways they have been used and deceived in the past. The Tuskegee experiments stand out in this regard. “They have been talked down to,” says Cross, “and they missed having compassionate experiences with American medicine.”

Often, Black Americans have not had hospice explained to them by people they trust. Cross works to help his patients understand how hospice will care for them. He encourage his patients to live their last days as fully as possible. Having respectful communications is key. People of color, Cross explains, are more comfortable talking about “the funeral they want” than they are about how they want to die. He also helps patients understand that they can receive hospice care at home or in a caring environment.

Cross has had patients share that they do not feel they can afford the care and support that hospice offers. He works to explain how the payment for hospice care works. He also engages patients, if they are able, in designing their own plan of care. Knowing that death is near can be difficult for patients, says Cross, but he has seen times when “the patient is ready but the family is not.”

Being an African American doctor, says Cross, makes a difference for the people he serves. They are often surprised to see a Black physician. But he understands these patients, talks respectfully with them, and makes eye contact.

“The No. 1 tool for a hospice doctor is not in their bag. It’s listening and communicating. People know when you are empathetic,” says Cross. He sees the need for an increased number of African American hospice providers of all disciplines. And, indeed, two of his children are training to be physicians. The first link below will lead to the article in *Star Tribune*.

Dr. Gloria Thomas Anderson and her team developed “Let’s Talk About ACP,” an initiative to create dialogue about end-of-life planning with faith and community-based groups in African American communities. Anderson notes the importance of the faith community and the value of the black church that “is considered a primary community source of trust...” In 2021, Pew Research found that “85% of African Americans hold some type of spiritual or religious beliefs, and that has been shown as a way to influence healthcare decision making, especially at the end of life.”

“Let’s Talk About ACP” is a train-the-trainer model that teaches and prepares faith- and community-based facilitators to engage their constituents in conversations around end-of-life care. Dr. Anderson’s resource book is titled “The African American Spiritual and Ethical Guide to End-of-Life Care: What Y’all Gon’ Do With Me?” Initial virtual workshops point to good outcomes and reflect active engagement of their constituents by those who attended the training.

The C-TAC article that shares about the “Let’s Talk About ACP,” cited at the second link below, also give a shoutout to Terrie James Taylor, Outreach Director at Montgomery Hospice. As a certified “Let’s Talk About ACP” facilitator, Taylor has offered “ACP training for 13 ministries in one of the oldest black churches in Montgomery County, MD.” (*Star Tribune*, 5/11, <https://www.startribune.com/st-paul-hospice-physician-explains-why-there-are-racial-disparities-in-end-of-life-care/600172300/>; C-TAC, 5/10, <https://www.thectac.org/2022/05/c-tac-exclusive-event-dr-gloria-thomas-anderson-and-the-importance-of-advanced-care-planning-in-african-american-communities/>;

AMERICAN ACADEMY OF PEDIATRICS ISSUES “GUIDANCE FOR PEDIATRIC END-OF-LIFE CARE”

The American Academy of Pediatrics has published “Guidance for Pediatric End-of-Life Care.” Authored by Jennifer S. Linebarger, MD, and Victoria Johnson, DO, the paper offers a deep dive into a myriad of issues that are involved in pediatric palliative and hospice care.

This is a clinical report that “reviews essential elements of pediatric care for these patients and their families, establishing end-of-life care goals, anticipatory counseling about the dying process (expected signs or symptoms, code status, desired location of death), and engagement with palliative and hospice resources. This report also outlines postmortem tasks for the pediatric team, including staff debriefing and bereavement.”

The lengthy and detailed article is available, in full, at the link below. It addresses many aspect of pediatric palliative care, from laying the groundwork to conducting autopsies to offering family bereavement care. The report concludes by noting that death does not follow in one trajectory. Early ACP is important, and the last days and weeks of life continue to provide opportunity to continue shared decision making and to be sure goals of care are met. Pediatricians are encouraged to collaborate with pediatric palliative care teams and with hospice.

Recommendation to pediatricians are offered by the authors, including the importance of:

- Engaging palliative care early on and opening “communication and decision making” with patients and families;
- Sharing decision making via a partnership of child, adolescent, and families;
- Beginning advance care planning soon after the serious diagnosis;
- Involving help, as needed, for facing issues like life-sustainment, ventilation, and medical nutrition and hydration;
- Helping with code status documentation;
- Identifying and discussing options for location of care during life’s last days or hours;
- Supporting families after death; and,
- Debriefing staff after the death.

(*American Academy of Pediatrics*, 4/25, <https://doi.org/10.1542/peds.2022-057011>)

HOSPICE NOTES

*** Sooner or later, hospices are going to be audited says Husch Blackwell.** Attorneys of Husch Blackwell’s Hospice Audit team, in an online podcast, look at the developments in hospice audits and offer “insight and guidance” on how hospices can face these challenges. Unified Program Integrity Contractor (UPIC) audits are increasing. The audit podcast, “Turning the Screws: UPIC Enforcement Tactics and What They Mean for Your

Hospice.” Podcast leaders “discuss the ways that UPICs can put pressure on hospices and how hospices can respond. (Husch Blackwell, 5/11, <https://www.huschblackwell.com/newsandinsights/hospice-audit-series-turning-the-screws-upic-enforcement-tactics-and-what-they-mean-for-your-hospice>)

*** “As Ohio’s Hospice looked to the future, it developed a new offering in healthcare—Pure Healthcare.”**

Now, Ohio’s Hospice and Pure Healthcare have been named as the “preferred hospice and palliative care” provider for Aetna’s VBID. Aetna patients, when referred to the provider, will also receive a case manager from Aetna, who will work with the hospice case manager. (*The Highland County Press*, Hillsboro, Ohio, 5/9, <https://highlandcountypress.com/Content/In-The-News/Headlines/Article/Ohio-s-Hospice-and-Pure-Healthcare-selected-to-be-Aetna-s-preferred-hospice-and-palliative-care-provider-in-Ohio/2/73/79019>)

*** The owner of three healthcare and hospice companies admitted to “stealing more than \$180,000 in COVID-19 relief funds that were intended for his healthcare and hospice businesses.** Javed Wahab, the owner of several hospices in Alameda County, California, has made a plea agreement. (*CBS Bay Area*, 5/6, <https://www.cbsnews.com/sanfrancisco/news/former-pleasanton-resident-pleads-guilty-to-stealing-186k-in-covid-19-relief-funds/>)

PALLIATIVE CARE NOTES

*** An article in *Home Health Care News* calls home-based palliative care “an untapped business opportunity for many home health and hospice providers in the U.S....” But several challenges continue to “hinder near-term scalability.”** For significant change, traditional Medicare benefits will need to change. The role of Medicare Advantage (MA) also needs to be followed. Edo Banach, president of NHPCO, says, ““What needs to happen is a mobilization of what...created the hospice benefit to begin with...”” (*Home Health Care News*, 5/5, <https://homehealthcarenews.com/2022/05/payment-patchwork-limiting-near-term-scalability-of-home-based-palliative-care/>)

*** “Home-Based Palliative Care Can Improve Quality of Life” appears in *Next Avenue*. The article profiles a patient and shares the story of a social worker who helped the family transition from hospital to home.** The family found the provider of palliative services to be a major source of support. They met the patient’s medical needs and assessed and addressed other needs. Research has shown, says the article, that home-based palliative care enables patients to decrease ER visits, inpatient days, needs for skilled nursing, and physician visits. And, the total cost of care for these patient is lower. Nevertheless, home-based palliative care is not yet available for most U.S. patients. Most palliative care is provided in hospitals. (*Next Avenue*, 5/9, <https://www.nextavenue.org/how-home-based-palliative-care-can-improve-quality-of-life/>)

*** An article in *ehospice* shares the story of Sally Wykes, a patient on home parenteral nutrition for nearly 32 years.** Wykes was interviewed as a part of the decade-old film “Life Before Death,” which highlights the value of palliative care. Wykes “was never afraid to die. But she was afraid of a lingering, painful death.” The article says the “nearly 90 percent of Americans have little or no understanding of what palliative care is at all.” The “Global Atlas of Palliative Care” estimates that “over 56.8 million people are estimated to require palliative care every year including 31.1 million prior to and 25.7 million near the end of life.” The article is found at the link below and includes links to “Sally’s Story” and other films. (*ehospice*, 5/10, https://ehospice.com/international_posts/capturing-the-lived-experience-of-palliative-care-patients-through-film/)

END-OF-LIFE NOTES

*** Apps for dealing with death are explored in a *Nerdwallet* article.** Before COVID, says the article, it wasn’t easy to get investors to buy into end-of-life planning. But the deaths and losses we have faced in the past two years have highlighted the need for planning for end-of-life. The article explores several of the apps, such as “Lantern, Cake, Empathy and Everplans” that are focused on planning for death and navigating life after a loss. Most of the apps are free and offer add-on tools for a fee. The article shares details about some of these apps. Engaging in this process, says the article, helps people reflect on what they value and how they want to be remembered. (*Washington Post*, 5/9, <https://www.washingtonpost.com/business/liz-weston-dealing-with-death-theres-an-app-for->

that/2022/05/09/4aebf89a-cf87-11ec-886b-df76183d233f_story.html)

*** Physician Jennifer Woodard recalls with gratitude her experience with a dying patient and his family.** The article, “Laughing in the Face of Death – Only the rare patient has a sense of humor,” appears in *Medpage Today*. She shares about the huge value of the patient’s sense of humor—that continued until his death. “While we cannot change the body’s ultimate fate,” says Woodard, “we have the privilege to guide our patients and families through this transition.” (*Medpage Today*, 5/9, https://www.medpagetoday.com/opinion/second-opinions/98608?xid=nl_secondopinion_2022-05-10&eun=g963454d0r)

*** In April, Boston Globe reported on a survey conducted by Suffolk University. The survey reported that 77% of adults believe adults with terminal illnesses should be able to end their lives with help from a physician.** Assisted dying continues to be an item of discussion in Massachusetts, and “lawyers are once again considering the issue.” *Greater Boston* shares a news feature that examines the issue. Guests include an advocate whose wife ended her life when terminally ill and a disability advocate who has serious questions about the law. The video of the presentation is online at *YouTube* at the link below. (*YouTube*, 5/5, https://www.youtube.com/watch?v=K0zNBicUMCQ&ab_channel=GBHNews)

*** A study reported in JCO Clinical Cancer Informatics examines the use of AI to help determine whether patients with an advanced solid tumor might have a prognosis of under six months of beginning a new LoT.** (Line of Treatment) The study says, “Clinicians often overestimate survival.” The study included 4,092 patients with solid tumors. The study created machine learning (ML) models. The “ML model” used “a limited set of 45 features readily derived from electronic health records...” to “predict 6-month prognosis in patients with advanced solid tumors.” Researchers believe the ML model might “support shared decisions making as patients consider the next LoT.” (*JCO Clinical Cancer Informatics*, March 2022, <https://healthitanalytics.com/news/new-machine-learning-models-can-predict-6-month-cancer-mortality>)

GRIEF AND ADVANCE CARE PLANNING NOTE

*** Susan Gibbons, a nurse at Hospice Buffalo, authored “Another Voice: Normal feelings of loss are being unfairly labeled.”** Gibbons argues that the decision by the American Psychiatric Association to name Prolonged Grief Disorder (PGD) in its manual of mental disorders is a mistake. The logic for the designation, she believes, is that a timeline was created so that insurers will cover counseling. The criteria for PGD, she says, “consists of a list of symptoms that virtually everyone who is grieving experiences.” As a grieving widow herself, Gibbons asserts that “grief cannot be remedied; one must learn to adapt.” And making these “intense emotions” become a pathology is “a prescription for failure.” (*Buffalo News*, 5/9, https://buffalonews.com/opinion/another-voice-normal-feelings-of-loss-are-being-unfairly-labeled/article_c8470a70-cf99-11ec-bed4-73100734abe1.html)

OTHER NOTES

*** TCN offers an audio program titled “AI Applications in Serious Illness” as a part of their TCN Talks.** Featured guest is Jeremy Powell, founder of Acclivity Health. Acclivity is “one of the few companies applying Artificial Intelligence (AI) and machine learning in the hospice and palliative care space.” Powell shares about the work his company is doing and the value it offers patients. (TCN, 5/6, <https://www.teleioscn.org/tcntalkspodcast/ai-applications-in-serious-illness-care>)

*** CVS Health is expected to get into offering care in the home. They recently “floated the idea of home health acquisitions and partnerships.”** Working with CVS’s own insurer, Aetna, CVS feels prepared to take this service on. *Home Health Care News* shares an interview with Aman Gill, director of product strategy and innovation at Aetna. Gill says he does not see home health and hospice providers as competitors. Instead, they are working with them as partners, “soliciting their help” and learning from them “what we may not understand for a plan perspective.” The interview is online at the link below. (*Home Health Care News*, 5/9, <https://homehealthcarenews.com/2022/05/cvs-health-using-home-health-hospice-providers-to-deliver-care-further-upstream/>)

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