

PRACTICAL BIOETHICS

Reframing “Do Everything” in African American Faith Communities

A 52-year old African American woman with chronic obstructive pulmonary disease was rapidly deteriorating. Doctors tried to explain her options: hospice or surgery to attach her to a ventilator for the rest of her life. Mom couldn't decide, her daughter said, because she didn't trust her doctors. She had nightmares about doctors hurting her.

Healthcare System Distrust

There are many well-documented explanations for African Americans' distrust of the healthcare system, their preference to “do everything” even when there's little chance of recovery, and the often painful consequences of avoiding hospice care. Only 18 to 24% of African Americans have an advance directive, and they are much less likely than other racial or ethnic groups to do formal advance care planning.



Gloria Thomas Anderson, Karen Bullock
and Julie Boudreau

Now, evidence is growing that African American faith communities can play a major role in reframing the meaning of “do everything” to include participation in advance care planning.

Engaging Churches

With support from the John and Wauna Harman Foundation and generous donors like you, the Center is refining advance care planning curricula for African



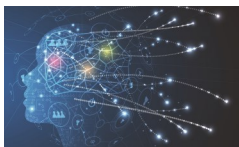
The African American Advance Care Planning/Palliative Care Network, which advocates for greater access and participation of African Americans in advance care planning, met in Durham, NC, July 31 – August 1.

American pastors, congregations and community organizations. Next year, we will present a variety of these curricula at five regional one-day training workshops for pastors and congregants representing 25 churches.

“The goal of the workshops is to prepare trusted advocates to seed advance care planning programs and ministries in their churches,” said John Carney, President and CEO of the Center. “Participants can then work with the Center in future years to lead continuing education efforts in their communities.”

Participants at the Durham meeting explored how we can promote advance care planning among African Americans.





The Promise and Pitfalls of Artificial Intelligence in Healthcare

People often perceive algorithms as superior to human judgment. What's wrong with that?

First, there's the black box problem. Algorithms are designed by humans who choose the data sets from which AI discerns patterns and bases decisions. We may not know what biases are built into these data sets.

Second, if you believe that an algorithm represents objective truth, you may be

less likely to seek a second opinion. Less likely to think critically. Less likely to take a risk. Or perhaps more likely to make a mistake.

Researchers are just beginning to explore such issues with respect to healthcare. What are implications, for example, of healthcare providers performing a procedure based solely on the results of an AI diagnostic tool?



The Center and Cerner convened a workshop on August 9 to explore the ethical dimensions of AI in healthcare.



Your support is helping the Center, in partnership with Cerner Corporation, develop an ethical framework and best practices for the creation and application of AI tools in healthcare.



Workshop participants brainstormed ways to ensure that new AI systems respect diverse needs of patients and users.

Ethics Committee Consortium You Help Clinicians Improve Care for Patients and Families

Mike, 27, had severe burns to his upper body from a fuel explosion. After a seven-month hospital stay, he had become verbally abusive to staff and refused care. "I'm done," he said.

The right of patients with capacity to refuse even life-sustaining treatments has been established and upheld in law and ethics for decades. However, with a diagnosis of bipolar disorder and substance abuse, Mike's decisional capacity was questioned.

Whose Values?

In cases like this, whose values should weigh most? The patient's right to autonomy, quality of life, freedom of choice and privacy? Or the clinicians' commitment to preserve life, do no harm, protect colleagues and uphold clinical standards?

On May 9, Ethics Committee Consortium workshop participants, led by Tarris Rosell, PhD, DMin, discussed Mike's and similar cases. The second half of the workshop, presented by Brian Carter, MD, explored the dynamics of family meetings.

Your Stake in Better Outcomes

As technology expands what medicine can do, your support enables ethics committees with proper training to help patients, families and clinicians determine what ought to be done, resulting in better outcomes for all concerned.

Find out about upcoming Ethics Committee Consortium workshops and webinars at PracticalBioethics.org or contact Matthew Pjecha at 816-979-1366.

Hospice Leader Has Three Strong Beliefs

Few can say that serving on a board of directors was a life-changing experience. Erwin Abrams is one of them.

One of four sons, Erwin grew up in Minneapolis in a family dedicated to social justice and landed on the staff of Menorah Medical Center in Kansas City after graduating from George Washington University with an MBA in healthcare administration. His understanding of bioethics' role in healthcare began here.

Erwin was the executive director of a community hospital in Florida in 1977 when his father was diagnosed with cancer.

"Once he understood the terminal nature of his diagnosis, my father decided he would accept one chemo treatment and then rely on comfort measures only," said Erwin. "This was opposed by my mother and his primary physician, but Dad stuck to his decision and lived comfortably in his last months."

Inspired to Serve

Erwin made the commitment to follow his father's wishes. He joined the board and eventually served as chair of Suncoast Hospice, led at the time by Mary Labyak, a trailblazing leader in hospice and palliative care. Meanwhile, he held a variety of senior executive positions with a hospital management company in the St. Petersburg-Clearwater area.

After devoting many volunteer hours to hospice, he decided to pursue hospice work 24/7. As CEO of Hospice of the Chesapeake in Annapolis, MD, from 1993 until retiring in 2009,

Erwin grew the organization from serving 50 to more than 400 patients a day and built the first hospice inpatient facility in the state.

Surrounded by Love

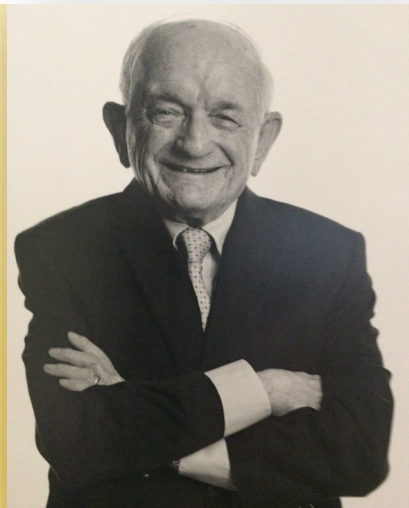
Today at 77, Erwin has three strong beliefs about end-of-life care.

"First, I'm a strong believer that patients ought to be in charge of their care at the end of life.

"Second, I believe that if you can control physical pain, all the other elements of saying goodbye can be managed. And, third, I believe that leaving this world surrounded by love, similar to how we are welcomed as infants, is healthy for both patients and those who love them."

Erwin met Center CEO John Carney at a hospice meeting in the 1980s. With Erwin's return to the Kansas City area in 2010, the two friends meet often.

"We're seeing ethical problems in healthcare multiply at a rate we can hardly keep up with," said Erwin. "What I wish people knew about the Center is how vital it is to the community."



Erwin Abrams

Presentations from the Flanigan Lecture and the Berkley Symposium are available at PracticalBioethics.org.



Jonathan Moreno, PhD, enjoys a moment with Sister Rosemary Flanigan on August 13 at the 25th Annual Flanigan Lecture, "America's Obsession: Having It All Without Paying the Price," held in her honor at the Jewish Community Center.



We were honored to have Kate Berkley, Janet Dubrava and Bill Berkley – Joan and Bert Berkley's granddaughter, daughter and son – as guests at the Symposium.



Jason Glenn, PhD, George Gotto, PhD, and Carla Keirns, MD, were panelists at the 12th Annual Joan Berkley Bioethics Symposium, "Perspectives on the Ethics of Genetic Engineering," held on August 14 at Kansas City University of Medicine and Biosciences.

Bioethics Case Studies Now Fully Searchable

Bioethics case studies can provide a roadmap for decision making in patient care. They also show how current standards of care have evolved from past ethical dilemmas.

Of 342,000 pages viewed at PracticalBioethics.org in 2018, nearly 55,000 were case studies. Your support for the Center is what makes it possible for us to provide these resources to students, healthcare providers, administrators and attorneys.

Still, we knew our case studies website pages could be improved.

The task was tackled this spring by two fourth-year Kansas City University of Medicine and Biosciences (KCU) medical students as part of clerkships towards their dual Doctor of Osteopathy/Master's in Bioethics degrees.

As a result of Michelle Amit and Brianna Cline's work, 65 case studies are now



Michelle Amit and Brianna Cline upgrade case studies archive.

divided into nine fully searchable topics with previews of each case.

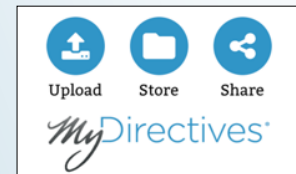
This Fall, Michelle began a pediatrics residency in Pensacola, Florida, and Brianna in internal medicine in Wichita, Kansas.

CASE STUDY TOPICS

- ✓ End of Life Care / Advance Directives
- ✓ Cases of Moral Distress
- ✓ Cases of Withdrawing / Withholding Care
- ✓ Access to Care / Vulnerable Populations
- ✓ Confidentiality
- ✓ Mistakes in Medicine
- ✓ Psychiatric Medicine / Duty to Warn



Make Your Healthcare Wishes Known



Picture this. You're in a coma with critical injuries from an accident. You signed a living will years ago, but no one can find it. Now family members gathered around your bedside are arguing about your treatment.

Then your son walks in. "Wait," he says, "Mom made a video telling us what she would want at a time like this. She uploaded it along with her Durable Power of Attorney for Healthcare to MyDirectives.com, and I have the password."

In that video, in your own voice, you made your values clear, including who should have the final say about what to do.

Your support for the Center makes it easy for anyone to upload, store and share advance care planning documents, as well as video, audio and medical orders at MyDirectives.com/cpb.

Get your free copy of our Caring Conversations® workbook guide to advance care planning at PracticalBioethics.org. Go through the process, upload results and enjoy peace of mind.

With your help, more people can receive the healthcare they want when it counts the most.

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