Black, Hispanic end-of-life views rooted in faith, family — and mistrust

by Cathy Lynn Grossman

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WASHINGTON (RNS) “A higher power will deliver me.”

“If Jesus suffered, I’m going to suffer.”

“I have a daughter, why would I need an advance directive?”

That’s what elderly African-Americans have told Karen Bullock, a medical sociologist and social worker.

Race, religion and a sense of the role of the family all play into end-of-life decisions for African-Americans, “and you cannot disentangle them,” said Bullock, a professor and head of the department of social work at North Carolina State University in Raleigh, N.C.

A new survey on end-of-life issues, released Thursday (Nov. 21) by the Pew Research Center’s Religion & Public Life Project, bears this out: Blacks and Hispanics are twice as likely as white Protestants, Catholics and people of no religious identity to insist that doctors do everything possible to stave off death, even in the face of incurable disease and great pain.

What’s more, the most recent statistics from the National Hospice and Palliative Care Organization show hospice service is overwhelmingly used (83 percent) by non-Hispanic whites. Less than 9 percent of hospice patients were black, and less than 7 percent were Hispanic.

Bullock, who is an African-American Southern Baptist, has tried to address end-of-life issues with a faith-based approach. She’s partnered with churches to talk about

advance directives and decisions about aggressive treatment, palliative care (shifting from efforts to cure to pain management in incurable cases) and hospice.

Even that didn’t work.

“I could talk about a good death, but I couldn’t convince them that medical providers were truly going to act on their behalf,” she said. Hospice may be the “gold standard of care at the end of life,” but minorities are not easily convinced, she said.

Bullock points to elderly African-Americans’ historic experiences for one reason they insist on aggressive treatment even in severe pain with an incurable disease.

This is the generation that lived through segregation and that remembered the infamous Tuskegee experiment, in which black men were injected with syphilis and studied but not treated, she said.

People who overcome adversity by relying on their faith in God are unlikely to change that in their last days, she said. “They believe death is not the end for them and they will pass on to a better place.”

They also have a different understanding of suffering.

“Suffering is not being able to feed your family,” Bullock said. “Lying in a hospital bed is not suffering.”

George Eighmey made a similar observation during his 12 years as executive director of Death with Dignity in Oregon, the first of four states that have legalized physician-assisted dying for terminally ill patients.

Eighmey, who retired in 2010, said he saw no black, Hispanic or Asian people inquire about the law before it was enacted, or after when it allowed people to obtain a lethal prescription from a physician and choose the day of their death.

He began an educational outreach program to all three communities to learn their concerns. Eighmey found Asians and Hispanics often rejected physician-assisted dying because they believe it is up to family members to “care for someone to the end.”

Hispanics and blacks, he said, also brought their deeply religious faith in miracles to their end-of-life views. They believe God is in control, not human beings.

Those few minorities who did, eventually, avail themselves of the Oregon law, he said, were largely “upper-income, highly educated, fiercely independent individuals who are accustomed to having things their way — pretty much like white people who have used the law.”

These are not people waiting passively for a miracle, said the Rev. Tarris Rosell, an ethics consultant at the Center for Practical Bioethics in Kansas City and an associate professor at the University of Kansas Medical Center, School of Medicine.

“If the patient or the patient’s family is praying for God to intervene, then everything must be done to keep Grandma or Grandpa going.”

Rosell, who was ordained in the liberal American Baptist tradition, said arguments over whether someone should continue aggressive treatment or turn to palliative care are a major reason he’s called in for ethics consultations.

Once, he said, a family came to him when their grandfather was already sedated, on a ventilator and unable to speak for himself. Their question: “Is it permissible to stop treatment, or is that a lack of faith?”

By stopping aggressive treatment, they feared they were saying that they didn’t believe in the power of God to heal.

“The miracle may be a release from suffering in this world,” he told them. “If God intervenes in the world to bring another kind of healing, wonderful! But then you don’t need doctors and machines. Maybe it would be best to turn them off and let God do what God is going to do.

“Faithfulness does not require us to keep someone in a state of suffering, to prolong the natural dying process. It’s our job as pastors to explain that at a certain point, the optimal level of care, which they always deserved, may be in letting go.”

This is not easy to convey to people accustomed to prayers such as, “Lord, be with the doctors,” said the Rev. Elree Canty, pastor at Grace and Mercy Christian Church, a nondenominational church in Lenexa, Kan.

“You will hear people say, ‘Lord, bless the surgeon’s hand and guide his mind to find a cure.’ If you shut that down, many feel you are closing the doors to a blessing,” Canty said.

“Everyone knows somebody who was on the verge of death and held on and kept fighting and, guess what, they bounced back!”

His mother did. Eight years ago, she was fighting breast cancer. “She was very aggressive about living.”

But, Canty said, his mother, now 60, also has written down all her desires for care if she falls ill again. Just in case.