

Breaking barriers

Doctors, patients must speak same language to bridge cultural divide

By LAVERA CRAWLEY

The cancer that entered Eva Washington's life was a masterful thief. Doctors had warned her about the illness lurking inside her. They even told her its name — acute myelogenous leukemia. They said she'd be dead in a few months.

But the illness stealing her life was so sly she couldn't see it. "No cancer," the 78-year-old black woman kept telling her white doctors. "I know I don't have it."

She had been seen by so many doctors for other complaints, undergone so many surgeries and tests, that she presumed any real cancer would have — should have — been found earlier. She found doctors untrustworthy; so she figured they couldn't really know what was wrong with her now.

In a way, she was right. Because of the grand canyon of miscommunication separating underserved minorities from a mostly white medical establishment, Washington's physicians had neither the training nor the clues to know whom they were dealing with.

How Washington lived and died speaks volumes about the challenges America faces in the coming years, as millions of baby boomers and their parents reach the dying stage of life.

Getting whites to face dying head-on and rethink the way they view life's end will be tough enough. But if society hopes to improve the way all Americans die, with dignity and quality care, it must first cross the cultural taboos and boundaries that appear to sit like trap lines around Asian-Americans, Hispanics, Native Americans and blacks.

In Washington's case, doctors could not know this: Far from the ravings of a mad woman, her refusal to accept her cancer and impending death were symptoms of a profound mistrust. Denial of a cancer diagnosis was part of Washington's struggle to get care she felt she'd been denied most of her life.

Doctors saw an obstinate elderly woman clearly dying of leukemia. Washington saw neglect.

That night in early 1998 she was brought into the emergency room at a San Francisco Bay Area hospital for chronic abdominal pain, something that for years had made her life hell. Tests confirmed what a recent bone marrow biopsy at another hospital had shown: acute myelogenous leukemia (AML).

And at the ER that night, doc-

tors focused on that recent diagnosis, not on the pain that had prompted her to come for help. In her mind, Washington couldn't have had AML, because her symptoms didn't match those she'd been told were part of leukemia — fatigue and fever, in particular. That prognosis didn't explain her chronic abdominal discomfort.

And by this point, the only thing real to her was pain.

Pain and how it's treated play a key role in America's cultural divide over end-of-life care. A 1998 study of nursing homes showed indigent black residents consistently reported their pain was inadequately treated as compared to that of white residents.

An earlier study in 1993 by Dr. Todd Knox of Emory University's School of Medicine revealed that Hispanics seen for fractures in a Los Angeles emergency room were twice as likely as non-Hispanic whites to be under-treated for pain.

But the subtext of pain in Washington's life was only part of a larger problem doctors couldn't see. How could she deny their prognosis, they wondered? Was she psychotic?

The real answer was that in the Tower of Babel of intercultural medical care, doctor and patient were really speaking two different languages: Washington spoke a black vernacular English. Her physicians used a specialized medical dialect.

Without access to the doctors' level of health literacy, Washington couldn't see any connection between her stomach pain and tests they had done on her bone marrow. So she misinterpreted their verdict of AML as a cancer of the bone. "But my bones don't hurt," she said at the time.

To complicate things, the doctors in that ER would not learn until long after she died that Washington's skepticism was not some wild paranoia, but a reality-based set of beliefs and anger that had been seething inside her for years.

Reformers have a huge language gulf to cross before the underserved get the same kind of end-of-life care with which white patients already are familiar. That's hardly news to doctors who work regularly with African Americans in the inner city or Indians in the deserts of the Southwest.

"The first thing you realize on the reservation is that you are at a distinct disadvantage for not speaking the language," said Dr. Chip Thomas, medical director of a Navajo health clinic. For 14 years, he has provided care, seeing pa-



For Norma Del Rio, an end-of-life counselor in San Francisco, language is only one of the cultural minefields in serving minority patients.

tients in the government-run health facility and on home visits, especially for those seriously ill.

"It's hard to do with every patient," he said, "but I find that it helps communication if I can see the patient in the context of their life, not just in the artificial environment of the clinic."

Cultural beliefs and practices influence doctor-patient interactions. In his 1995 study, Dr. Joseph Carrese reported in the *Journal of the American Medical Association* that sharing bad news with patients of certain ethnic groups can cause harm if not done in a way that recognizes cultural values. In fact, even raising the possibility of a bad outcome can be seen as wishing that outcome on the patient.

"I'm aware that everything I say has some cultural meaning," Thomas said. "My Navajo patients are sensitive to health-care providers who know about the cultural taboos and understand that word sounds have power."

Those who work with Latinos have their own cultural minefield. "With Latinos, you may have complex problems, and language is one of them," said Norma Del Rio, an end-of-life expert with the San Francisco health department. "Monolingual patients may rely on family members to act as translators, and this can be a source of communication breakdown."

Del Rio added that in some Hispanic groups, there's a tendency to equate open discussion of death with loss of hope. "Families may want to shield their loved one from serious diagnoses," she said, adding that what some might see as denial is really "terror management."

Finally, Del Rio said some Asians bring a curious twist to lin-

guistic etiquette. "With some of the Asian families we serve," she said, "patients and families expect doctors to discuss health concerns with the family spokesperson, usually a son or daughter, and not directly with the patient."

And this miscommunication isn't limited to ethnicity. Gay and lesbian patients often find their sexuality becomes a barrier to open discussion about life-and-death issues.

"The problem gay and lesbians confront is that physicians are uncomfortable with sexuality in general," said Paul Brenner, executive director of Jacob Perlow Hospice at Beth Israel Medical Center in New York. "When physicians deal with sexual diversity, their discomfort and sense of judgment make it difficult for gay and lesbians to talk openly about the real issues surrounding their illness and how it really affects their lives," including the physical effects of ravaging illness and the stigma of AIDS.

As with many minority patients, miscommunication and distrust had been simmering in Eva Washington for a while. Ten years ago, she had undergone back surgery and was soon tormented by severe abdominal pain.

She began an endless search for relief. "I was trying to get someone to tell me exactly what was happening to me," Washington said shortly before she died, four weeks after that last diagnosis in the ER. "They take the X-rays. They give me every kind of test. But I still don't know any more than I did before I went to the doctors."

Not surprisingly, frustration brought Washington to a troubling thesis: The reason doctors would-

n't identify and treat her pain was that during that first surgery some medical error must have occurred. And she assumed the error was apparent to every subsequent doctor who examined her.

By the time she arrived at that ER in 1998, Washington was carrying inside her a full-blown conspiracy theory. And like many minority patients, it not only colored the way she viewed the medical world, it compelled her to dismiss any new diagnosis as bunk.

If the movement to transform Western culture from one that is death-denying to one that deals with the physical, emotional and spiritual suffering of people who are dying, walls like the one that separated Washington from her doctors must be knocked down.

But that may be the easy part. In another curious twist of the cultural complexities involved in end-of-life care, some experts say African-Americans are more likely to want aggressive life-sustaining interventions, as compared to whites. "Everybody wants to go to heaven, but nobody wants to die," said the Rev. Frank Jackson, a black Presbyterian minister in the Bay Area. "It's not so much the act of dying itself, but the things that are surrounding death: injustice, poverty, mistreatment and evil."

Washington's resistance highlights a major barrier to minority participation in programs like hospice and palliative care services designed to relieve suffering. Instead of being viewed as compassionate comfort to help bring dignity to dying, the veterans of health-care inequities see such programs as medical abandonment.

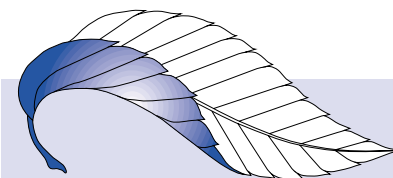
"There's a sense," said Jackson of terminal illnesses, "that we won't be stopped by those things — it's our 'somehow theology.' Somehow, some way, we will get through this."

Washington, of course, did not. She died within a month of her last hospitalization, having never accepted her condition. At her funeral, a nephew eulogized her as someone who'd "go down fighting" and "never let the doctors have the last word."

But his words rang with irony. Washington did go down fighting. But if anyone had tried to get her and her doctors to understand each other, she might have realized that she really didn't have to.

"Eva Washington" is a pseudonym. To avoid any ethical breaches, the subject's real name could not be used. She was a participant in a research study in which her anonymity was assured.

For more resources on end-of-life issues, go to www.findingourway.net.



FINDING YOUR WAY

COPING TIPS

If you're a minority facing a life-threatening illness, it's vital to have access to medical information that's understandable, respectful and culturally appropriate. Here are some tips to open the lines of communication for patients, families and their health-care providers:

If you or an ailing family member does not speak English, insist on the services of trained medical interpreters who not only can provide translation but also help you negotiate across the cultural divide of medicine and community values. Depending on your community, many health-care facilities offer medical translation services. If they don't, commercial medical translating services, including AT&T Language Line® Services (800-752-6096 or www.language-line.com), may offer an alternative.

When communication gets bogged down, patient advocacy services, available at many medical centers and hospitals, can help you navigate through the system. Ask your community hospital about its patient relations or patient advocacy office.

The odds of finding services that respect your heritage increase dramatically if staffing and volunteers at health facilities reflect the communities they serve. Consider volunteering at hospices, end-of-life organizations and other medical institutions.

—LaVera Crawley

WEB SITES

Tuskegee University National Center for Bioethics in Research & Health Care, 1209 Chambliss St., Tuskegee, Ala. 36088; (334) 724-4612: The nation's first bioethics center devoted to engaging the sciences, humanities, law and religious faiths in exploring moral issues involving research and medical treatment of African-Americans and other underserved people; www.tubiethics.org.

Assuring Cultural Competence in Health Care: The Health and Human Services Office of Minority Health offers national standards on health services that respect language and culture; www.omhrc.gov/clas/index.htm

HIVinSite: The University of California San Francisco offers comprehensive information on issues surrounding HIV/AIDS; <http://hivinsite.ucsf.edu>

Growth House Inc. (415) 255-9045: Provides background and health agency referral services with a strong focus on diversity, including a section on gay and lesbian issues; www.growthhouse.org/

ACCESS to End-of-Life Care, P.O. Box 460478, San Francisco, Calif. 94146-0478: Offers information about death, dying and grieving from a multicultural perspective; (415) 566-9710; www.access2eolcare.org

BOOKS

"Cultural Issues in End-of-Life Decision Making", edited by Kathryn L. Braun, James H. Pietsch and Patricia Blanchette (Sage Publications Inc, 2000; no price available)

"The Spirit Catches You and You Fall Down," by Anne Fadiman (Farrar Straus & Giroux, 1997; \$12.60)

"Facing Death: Where Culture, Religion and Medicine Meet," edited by Howard M. Spiro, Mary G. McCrea Curmen and Lee Palmer Wandel (Yale University Press, 1998; \$16.95)

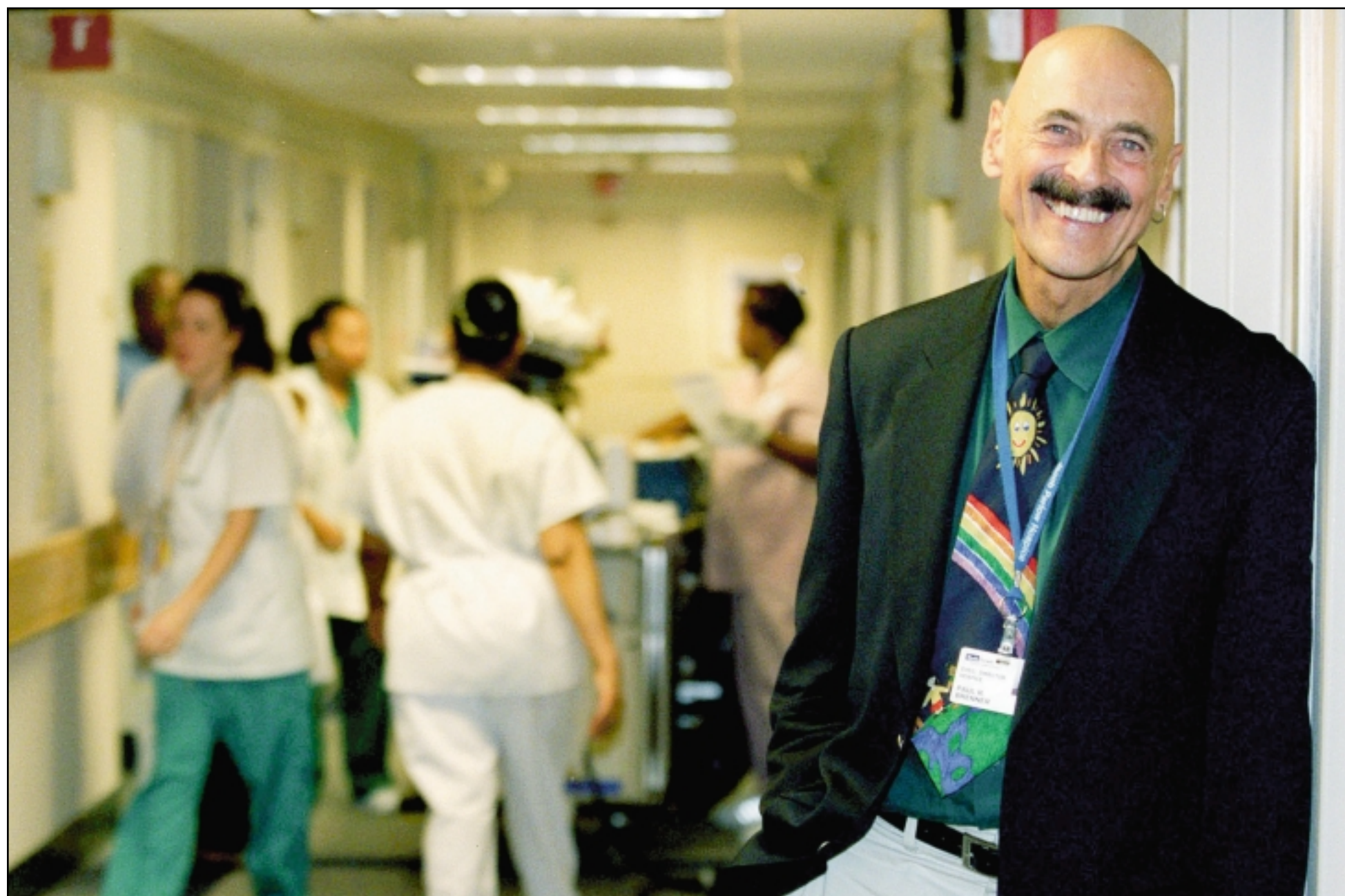
VIDEO

"Worlds Apart": A broadcast documentary film and medical education project that tells the stories of patients, families and doctors as they make critical medical decisions, and portrays their lives, cultural perspectives and communities. Contact the Filmmaker-in-Residence Program at the Stanford Center for Biomedical Ethics; (650) 723-5760; <http://scbe.stanford.edu>

For more resources, go online to www.findingourway.net

ABOUT THE AUTHOR

LaVera Crawley is a lecturer at the Stanford University School of Medicine in Palo Alto, Calif., and the executive director of the Initiative to Improve Palliative and End-of-Life Care for African-Americans. Crawley has served as project director for Research on Cultural Diversity and End of Life at Stanford's Center for Biomedical Ethics. She is a former Soros Faculty Scholar for Project on Death in America and has published extensively regarding cultural barriers to end-of-life care.



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