equal treatment

CEDREC digs at the roots of disparities in medical care

By Sharon Tregaskis

Erica Phillips-Caesar’s last patient that day would be her toughest. An African American woman in her late fifties, she arrived at her initial appointment forty-five minutes late, after having canceled three previous appointments, complaining that her legs were swollen. “I had a hard time pinning down the woman or her daughter for a history,” recalls Phillips-Caesar, MD, an assistant professor of medicine at Weill Cornell. “I remember being frustrated and feeling bad: why can’t you get your act together, show up on time, tell me your story, help me understand what the problem is?”

Finally, Phillips-Caesar concluded the interview and left the room while her patient undressed for a physical exam. When the young physician returned, it was immediately clear that her patient’s leg symptoms were the least of her medical concerns. “There was a huge, cancerous mass in her breast,” says the doctor. “It was visually apparent.” The woman was in complete denial, as was the daughter who had accompanied her to the appointment—despite the fact that the woman’s regular doctor had been advocating a biopsy for a year and the daughter had been aware of the mass for some time.

When she was finally diagnosed, the patient had Stage IV cancer. She had health insurance and access to doctors. Yet despite Phillips-Caesar’s urging and the advice of her regular physician, the woman never took advantage of the care available to her. Often, she simply skipped her appointments. “How in the world does that happen?” asks Phillips-Caesar. “What is it about our health-care system, us as providers? Did she understand, in no uncertain terms, that this was cancer? Was her health literacy or overall literacy so low she couldn’t understand? Is it about her faith, her comfort with her death, that this was meant to be?”

Within six months, the woman was dead. With early intervention, her chances of survival would have been close to 90 percent.

Epidemiologists and policymakers have long known that minorities have reduced access to health care, take less advantage of screening, receive later diagnoses, and generally have poorer outcomes than their white counterparts. Black women like Phillips-Caesar’s patient may be less prone to developing breast cancer, but their disease is more apt to be diagnosed at an advanced stage, and they are more likely to die of it within five years. African Americans, Mexican Americans, and Native Americans are all more likely to develop diabetes than their white counterparts and far more likely to develop complications or die from the condition. Minority nursing home residents are more likely to go without glasses or hearing aids. Non-whites are less likely to receive standard treatments for asthma during childhood, and they have worse outcomes and lower quality of life following a heart attack.

Financial considerations undeniably influence who gets medical care in the U.S. and how good that care is; to those without health insurance, such essentials as screening, preventive care, and treatment can seem equally unaffordable and inaccessible. Yet finances account for only part of the story. “What is particularly disturbing is that despite the economic explanations, there seem to be additional situations and
areas where our health care is not equal,” says Alvin Mushlin, MD, ScM, chair of Weill Cornell’s Department of Public Health. “When we adjust or equalize for economics, important differences remain in the degree and quality of health care that certain citizens in our country receive.”

Mushlin trained in the South, back when black hospital patients were admitted to segregated wards and only white physicians had full privileges. “Today what I see as a clinician in New York is a vastly different situation than was the case in Tennessee in the early and mid-Sixties,” he says. “Back then, the causes for racial and ethnic disparities were right in front of your eyes, part of the segregated South. Those overtly discriminatory practices have been removed, but we still see disparities that shouldn’t exist in what we all hope is a much more egalitarian society.”

In January, the National Center on Minority Health and Health Disparities, a division of the National Institutes of Health, awarded Weill Cornell an $8 million grant to establish the Comprehensive Center of Excellence in Disparities Research and Community Engagement (CEDREC), a consortium of scientists at the Medical College and colleagues at the Hunter College School of Nursing, the City University of New York, Lincoln Medical and Mental Health Center, and the Center for Healthful Behavior Change at the New York University Langone Medical Center. Carla Boutin-Foster, MD, the Nanette Laitman Clinical Scholar in Public Health/Community Health and an associate professor of medicine at Weill Cornell, is the director. Mary Charlson, MD, the William T. Foley Distinguished Professor of Medicine and chief of the Division of Clinical Epidemiology and Evaluative Sciences Research, is a co-director for CEDREC and director for the research training core; Mushlin co-directs the research core; and Phillips-Caesar co-directs the core for community engagement and outreach.

“In approaching disparities research, a lot of it is about cultural competency, understanding from a community standpoint how culture plays into disease,” says Phillips-Caesar. “If we have the answers to these community issues—if we help the communities build their capacity to get to the heart of the matter and articulate why these disparities exist—then we could eliminate them.” Understanding that dynamic might have boosted her own long-ago patient’s chances for survival, she says. “Often, minority patients come to a provider already having talked to
To ensure that research tackles issues relevant to the people who are served by Weill Cornell’s Comprehensive Center of Excellence in Disparities Research and Community Engagement (CEDREC), director Carla Boutin-Foster, MD, and her collaborators assembled a community advisory board. The membership includes adult literacy professional Estella Natal, a native of Puerto Rico who has worked for the New York City Department of Health teaching health literacy to immigrants and for CEDREC partner Lincoln Medical and Mental Health Center promoting cultural sensitivity. Natal offers these tips for working with underserved populations—both as patients and as study participants. Success, she says, boils down to a single concept: marketing. “Marketers know these things by heart,” she says. “People in health and education don’t.”

- **Use plain language.** “The key is to keep the sentences and paragraphs short and simple,” says Natal, to make materials accessible to those with limited English literacy. “Stay away from words with three or more syllables. Instead of ‘hypertension,’ say ‘high blood pressure.’”

- **Know your audience.** “Be careful with references like sports,” cautions Natal, who this summer rewrote a series of documents that had employed baseball as a metaphor. “Soccer is the most popular sport in the world,” she says. “Use baseball, you leave out some people.”

- **Be aware of symbolism.** Among some Asian cultures, for example, white represents death, mourning, and ghosts. “In some hospitals,” says Natal, “they’ve changed the sheets to beige.”

- **Think positive.** When tackling issues of obesity and weight loss, promote “healthy eating.” To connect with people suffering from domestic violence, who might be in denial or defensive about their situation, focus on “healthy relationships.” Says Natal: “Even if they’re a victim, they’ll say, ‘That’s not me.’”

- **Consider the context.** “You can’t tell someone who’s Latino, ‘Don’t eat rice and beans.’ They won’t listen,” says Natal. “You talk about smaller starch portions and encourage more fruits and vegetables.”

- **Don’t judge.** Says Natal: “You take a perspective of gently coaching, instead of telling people what to do.”

For minority communities whose distrust of mainstream medical professionals traces its roots to the Tuskegee Institute’s studies of syphilis and the overt racism of America’s early history, such collaboration can be thorny. As a consequence, says Boutin-Foster, forging relationships with community partners can be slow going at first. Ultimately, however, time invested early on yields enhanced study participation and more relevant findings. “They’ll tell us if a question is offensive or doesn’t get at the information we’re trying to collect,” she says. “It may take longer. But just saying, ‘We’re recruiting patients,’ doesn’t always work. You can hang up a flyer and say, ‘Please come,’ but not many people will. You can’t recruit people without buy-in.”

If researchers don’t understand local priorities and concerns, says CEDREC co-director Mary Charlson, they can end up investigating problems of limited concern...
to the people they’re trying to help—or propose solutions that simply aren’t feasible. “Nobody knows the problems in a given community better than the people who live and work there,” says Charlson, who is working with Phillips-Caesar on Small Changes and Lasting Effects (SCALE), a study to develop effective behavioral interventions and mindful eating strategies for overweight and obese black and Latino adults from the Harlem and South Bronx neighborhoods targeted by CEDREC. “The solutions that work in a homogeneous white population—for example, Rochester, Minnesota—are not necessarily applicable or relevant to people in the South Bronx.”

In the largely African American and Latino communities of Central Harlem and the South Bronx, poverty is endemic. So are obesity, diabetes, and hypertension. Thirty-two percent of residents lack a high school diploma, 15 percent go without health insurance, and 23 percent lack a primary care physician. In the two communities, the rates of hypertension—a major risk factor for cardiovascular disease, kidney disease, stroke, and heart attacks—are the highest in New York City. In a 2008 study, Boutin-Foster and longtime collaborator Gbenga Ogedegbe, MD, MPH, an associate professor of medicine at New York University and director of CEDREC’s research core, reported that while 30 percent of African Americans nationwide keep their blood pressure under control through a combination of exercise, prescription medications, and a low-salt, low-fat diet, in Central Harlem and the South Bronx, it’s just 5 percent.

To boost those numbers, Boutin-Foster launched a program called Trial Using Motivational Interviewing and Positive Affect and Self-Affirmation in Hypertension (TRIUMPH) while Ogedegbe serves as principal investigator of the Multibehavioral Intervention to Increase Screening and Enhance Risk Reduction in Black Men (MISTER-B). TRIUMPH recruited patients from the Renaissance Health System, a CEDREC partner. Half are assigned to a patient-education program that emphasizes improved diet, increased exercise, and consistent use of medication to control blood pressure. The test group participates in the same education program, supplemented with a motivational component. “We help people emphasize the positive, focus on their inner strengths,” says Boutin-Foster. “They know they have to control their blood pressure, yet they do not. Instead of saying, ‘If you don’t control it, you’ll get sick,’ you talk about ‘What are things you can do?’ and ‘What are ways you’ve been successful in the past?’ It’s building a positive reserve in the patient and talking about the benefits.”

MISTER-B builds on a more fundamental challenge Ogedegbe encountered in his patient work. “Black men don’t go to the clinic,” he says. So Ogedegbe and collaborator Joseph Ravenell, MD, an assistant professor of medicine at NYU, decided to stop waiting for them and instead send specially trained community members to meet prospective patients where they are—in barbershops—and facilitate the logistics of screening, follow-up, and case management. “Colon cancer and hypertension are the two killers of black men,” says Ogedegbe. “If we can capture men who are at high risk and use health-care navigators to get them to clinics, it can be good for the country.”

Perhaps even more important than the data that emerges from SCALE, TRIUMPH, and MISTER-B are the relationships being forged—among scientists at Weill Cornell, NYU, and the Center’s other partners; among researchers and community representatives; and among established scientists and the graduate students they mentor. “People who grow up in a given cultural context are more likely to work in that area,” says Charlson. “If you want to study the Korean community as a white, middle-class woman, you could do that—but you’d have to immerse yourself in the community and learn the language. Otherwise, you’re not going to be able to do effective behavioral intervention.”