Can Patient Navigation Help Resolve Gaps in Cancer Care?

By Mike Fillon

Earlier this year, Carmen Navarro-Matthews approached a 53-year-old black woman at a health fair in New York City, suggesting that she get a mammogram and colonoscopy. The woman was uninsured and opted to get both exams at the Ralph Lauren Center for Cancer Care and Prevention through its philanthropic grant program. She was diagnosed with triple-negative breast cancer and had a total mastectomy of her left breast.

Without Navarro-Matthews’ help, the woman probably would not have received the care she needed. But Navarro-Matthews, an outreach patient navigator for the Lauren Center, helped guide her through the entire health care maze, including financial, treatment, and follow-ups.

Navarro-Matthews, who has been a patient navigator for 5 years and has an M.S. in public policy, sees patient navigators as an essential link in efficient cancer care. “When [patients] get a diagnosis of cancer, they’re in a fragile state and there’s a lot of information for them to digest. Patient navigators can keep them on track with the next steps in their treatment plan, which is crucial for people who haven’t had much experience with the medical system,” she said.

Although cancer mortality rates in the U.S. have dropped substantially over the past few decades, not everyone in society has benefited equally. With few exceptions, racial and ethnic minorities—especially if they are poor—continue to have disproportionately high incidence and mortality rates from cancer.

The American Society of Clinical Oncology (ASCO) has been looking into these issues for years. In August, it released a policy statement outlining provisions of the 2010 Patient Protection and Affordable Care Act (PPACA) that ASCO believes could lower these disparities. Shortly after President Obama signed PPACA into law on March 23, 2010, ASCO’s Disparities Committee met to discuss how the legislation would affect cancer care.

“We all realize in the cancer world we have a completely disjointed system that is very difficult for patients to navigate, seeing the specialists they need and ensuring they followed up on test results,” said Blase Polite, M.D., a committee member and assistant professor of medicine at the University of Chicago.

Polite said the committee recognized health care reform focused on the primary care side and gave little thought to cancer care. “So, we studied it looking specifically for the things that could help us move the ball forward in terms of reducing health disparities and what challenges still remained,” he said.

As a result, ASCO’s statement, in the Aug. 14 Journal of Clinical Oncology, makes recommendations to ensure that such provisions are carried out effectively and urges additional steps to address systemic issues including insurance reform, quality of care, prevention, research, and diversity in the health care workforce. Their recommendations include the following:

- Adopting patient-centered quality-improvement initiatives
- Attracting more minority physicians and improving the training of the oncology workforce to meet the needs of racially and ethnically diverse patients
- Improving data collection on cancer disparities and determining what must be done to make meaningful medical evaluations
- Ensuring access to cancer specialists for all patients who seek treatment at federally qualified community health centers
- Allowing cancer-centered services to be at the direction of oncology professionals in community health centers and medical homes, where many seek medical care

Scope of the Problem

It’s indisputable: Individuals of all ethnic backgrounds who are poor have inadequate access to high-quality cancer care, resulting in poorer outcomes. The National Cancer Institute defines cancer health disparities as the differences in the incidence, prevalence, mortality, and burden of cancer and related adverse health conditions that exist among specific population groups in the U.S.

The reasons for higher cancer incidence and mortality rates from cancer are well documented: socioeconomic and genetic factors; lack of knowledge; inadequate access to care; cultural competence of health care providers; lack of participants in clinical trials; patients’ difficulty in understanding the complexity of the health system in general; and, of course, fear, frustration, and lack of knowledge.

As a result, NCI data show that for all cancers combined, the death rate is 25% higher for blacks than for whites. Here are a few more examples:

- Although white women have the highest incidence rate for breast cancer, black women have higher breast cancer death rates.
- Black men have the highest incidence rate for prostate cancer in the U.S. and are more than twice as likely as white men to die of the disease.
- Black men and women have the highest incidence and death rates for both colorectal and lung cancers (Hispanics/Latinos have the lowest rates).

Many studies have set out to decipher these differences. One, which screened more than 60,000 people for colorectal cancer, found that the higher rates of colorectal cancer incidence and mortality in black people were due largely to insufficient health care access. In the study, which
was part of NCI’s ongoing Prostate, Lung, Colorectal, and Ovarian Cancer Screening Trial (PLCO), and was published in the April 21, 2010, issue of the Journal. Researchers found that American blacks and whites were equally likely to need a follow-up colonoscopy after a screening sigmoidoscopy but that they were less likely to actually receive the follow-up.

“Our research suggests that the biology of colorectal cancer may not differ by race, at least in the early stages of tumor development,” study author Adeyinka O. Laiyemo, M.D., M.P.H., from NCI’s Division of Cancer Prevention said in a statement. “Instead, health care utilization differences among races may play a more important role in colorectal cancer disparities.”

Furthermore, in a study published Oct. 12 in the Journal, after examining data from the Adjuvant Colon Cancer Endpoints (ACCENT) collaborative group database, researchers found that black patients with resected stage II and stage III colon cancer experienced worse overall and recurrence-free survival than whites but had similar recurrence-free intervals. Although researchers have long recognized similar differences between races and have suspected a biological basis at least in part, navigators should have clearly defined roles that distinguish them from other health care providers. “A good patient navigation system should eliminate the ‘turf’ wars that sometimes exist between nurses, social workers and others that can negatively impact patients.”

**Role of Patient Navigators**

Getting at health care usage often involves a more direct approach, and patient navigators have a vital role in helping people get through the health care system. “Right now we have a bunch of different silos throughout the system,” said Polite. “Even the Community Health Center Model for integrated health care, which is a fantastic model, is still very much primary care focused. The National Quality Care Foundation and the American College of Internal Medicine have said you need non-_physician care managers to coordinate that care and get through the disjointed system, and that’s what a navigator or care manager does.”

Harold P. Freeman, M.D., a Harlem, New York–based surgical oncoligist, coined the term patient navigation two decades ago, to redress local disparities—and specifically to improve access, diagnosis, and treatment of cancer, particularly among poor and uninsured people. “Too often, people fall between the cracks for a number of reasons,” said Freeman in an interview. “Poverty should not be an offense that is punishable by death.”

Freeman sees patient navigation as a natural fit with ASCO’s goals. Described as a community-based intervention to ensure that people with or suspected of having cancer get the tests and treatment they need, aided by people who look and sound like them, patient navigation consists of nine principles that Freeman developed. At the heart of this is a patient-centric approach. “Patient navigators are involved every step of the way, including diagnosis, insurance matters, and rehabilitation up to the end of life,” said Freeman. For their part, navigators should have clearly defined roles that distinguish them from other health care providers. “A good patient navigation system should eliminate the ‘turf’ wars that sometimes exist between nurses, social workers, and others that can negatively impact patients,” said Lovell A. Jones, Ph.D., director of the Dorothy I. Height Center for Health Equity and Evaluation Research at the University of Houston and the University of Texas M. D. Anderson Cancer Center.

Freeman also said a truly functional navigation system requires specialists for a spectrum of phases of patient care, from screening to financial issues. “Every aspect of care must be covered by navigators,” said Freeman. “Until about 6 years ago, we had one navigator navigate a patient from the beginning to the end. We have now separated out a few specialties, such as financial navigators, so they can focus on what they know best.”

There is evidence that patient navigation works. A study published in the February 2003 *Journal of the American College of Surgeons* found that among 606 breast cancer patients—94% of whom were black—treated at Harlem Hospital Center over a 22-year period, the 5-year survival rate was 39%. Once the hospital added a patent navigation model designed by Freeman, which ensured that all patients received timely diagnosis and treatment along with free or low-cost examinations/mammograms, the 5-year survival rate jumped to 70%. Although the increased survival is partly attributable to the availability of the tests, Freeman says the dramatic improvement wouldn’t have been possible without patient navigation. When patients are moving through the maze of departments without oversight, they often get lost, said Freeman. “Patient navigators make sure they get to where they need to be when they need to be there throughout their ordeal.”

Largely on the basis of the success of Freeman’s patient navigation model, President George W. Bush in 2005 signed the Patient Navigator and Chronic Disease Prevention Act (HR 1812). This legislation funded more than 20 patient navigation demonstration sites, and in 2007, a $2.5 million foundation grant established the Harold P. Freeman Patient Navigation Institute in Harlem.

**The Cost Factor**

With the national health care debate focused on cost cutting, adding patient navigators
could seem like an unnecessary luxury. Not so, according to both Jones and Freeman.

Jones said patient navigators can play an integral role in the changing health care environment in several ways: by facilitating access and addressing language, culture, literacy, communication, and other barriers. “[Patient navigators] can help deliver better quality and more efficient care. Just look at the millions saved if we can eliminate clogged emergency rooms running up astronomical tabs,” said Jones, who co-wrote a study in the July 20, 2011 issue of Cancer entitled “The Role of Patient Navigators in Eliminating Health Disparities.”

Freeman said one way to save money in the medical care system is to be sure that people are rapidly diagnosed for cancer so they can receive timely treatment—and patient navigators could be crucial to facilitating an early diagnosis. “Society has to realize that somewhere along the line we’re going to pay for that cancer patient. It would be much, much cheaper to detect cancer early and treat it.”

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