SERVING THE UNDERSERVED

3 Model Community Cancer

by Marion Dinitz

Cancer is not affecting all Americans equally. Studies have shown major disparities in access to quality cancer care—from screenings and diagnosis through access to state-of-the-art therapies and end-of-life palliative care. The National Cancer Institute reports that disparities in the incidence and mortality rates for all cancers widened significantly over the last three decades.

This unequal burden of cancer among minorities and the underserved is measured by several indicators, including incidence, mortality, and survival rates. The overall annual incidence rate for all cancer sites is highest among African Americans (516 per 100,000) as compared to Caucasians (480 per 100,000), Asian/Pacific Islanders (337 per 100,000), Hispanic/Latino (351 per 100,000), or American Indian/Alaska Native (238 per 100,000), according to the National Cancer Institute.

People of all ethnic backgrounds who are poor, lack health insurance, or otherwise have inadequate access to high-quality cancer care are typically less likely to receive cancer screening services and more likely to have late-stage cancer when the disease is diagnosed. As a result, a disproportionate number of cancer deaths occur among racial/ethnic minorities and the poor.[1]

Underserved populations face numerous barriers, including:

- Inadequate access to care
- Mistrust of the healthcare system
- Fear and fatalism
- Lack of knowledge of cancer prevention and screening recommendations
- Lack of cultural sensitivity
- Financial burden.

To address these cancer-related health disparities, an important first step is to identify those critical components of effective cancer prevention programs that are specific to the targeted minority and underserved populations. Three model community cancer programs have made serving underserved cancer patients their mission. Here are their stories.

The Ralph Lauren Center for Cancer Care and Prevention

by Marion Dinitz

Harold P. Freeman, MD, has worked in Harlem for more than 35 years. A leading authority on the interrelationship between race, poverty, and cancer, Freeman has concluded that poverty, not race, is the principal cause of the high cancer death rate in Harlem and that poverty is a universal cause of low cancer survival.

Through Freeman's vision and ardent efforts, an innovative partnership was formed so the Ralph Lauren Center for Cancer Care and Prevention could open its doors in East Harlem, New York, in May 2003. The center provides Harlem's African American and Latino populations, many of whom are medically underserved, with access to the highest quality cancer screening and treatment services.

The Ralph Lauren Center brings together the expertise of one of the nation's leading cancer centers, Memorial Sloan-Kettering, and North General Hospital, a community teaching hospital serving the Harlem community for more than 25 years. The center was built thanks to a generous $6 million grant from world-famous clothing designer Ralph Lauren, who has been committed to the fight against cancer for more than 15 years.

Each month, more than 500 patients visit the center, which is staffed by two surgeons, one of whom is Freeman, the center's medical director; two medical oncologists; and three nurses, who are committed to ensuring that community residents receive the best possible cancer care and services right in their own neighborhood.

The cancer center provides screening services for colon, prostate, cervical, and breast cancers, and offers chemotherapy on site. A physician is always on site when chemotherapy is being administered.

The center also plans to conduct research to advance the understanding of the cultural factors that influence cancer care and improve health outcomes of medically underserved communities. Freeman is currently talking with breast care specialists at Memorial Sloan-Kettering about how best to accrue indigent patients from Harlem into certain clinical trials underway at Sloan-Kettering. Freeman maintains that it is a matter of not only educating the indigent about clinical studies but also gaining their trust about participating in such innovative treatments.

One of the most innovative services provided by the cancer center are patient navigators, a concept pioneered by Freeman. The three patient navigators currently on staff are either African American or Hispanic and hold either high school or college degrees. (See Freeman's arti-

Programs

Exterior and interior views of the Ralph Lauren Center for Cancer Care and Prevention in East Harlem, N.Y.

cle in the September/October 2004 issue of *Oncology Issues* on the patient navigator program.)

The center has an agreement with the New York State Health Department to receive a special Medicaid rate, which is higher than the average Medicaid rate in the city of New York, said Freeman. Some financial assistance also comes from Memorial Sloan-Kettering. The center operates on a fee-for-service basis, but tries to convert the uninsured to insured status so the patient can be better served through the healthcare system and the center can also be reimbursed for its services.

"If you're uninsured and the doctor says you need a biopsy and you're out there by yourself, you could easily get lost in the healthcare system," said Freeman. "Of the uninsured people that are served by the center, the patient navigator is able to successfully obtain insurance coverage for 95 percent of them so they can go ahead with their surgery."

In addition to its patient navigation program, the center offers consultations, referrals, education, and outreach efforts. The beautifully designed 10,000-square-foot center has additional space that allows for 3,000 square feet of future expansion. Future plans include adding such services as pain management and palliative care.

The center features a warm, friendly environment offering patients personalized attention. A director of guest services greets all visitors, making sure that they feel comfortable and are attended to. The goal is for visitors to feel like they are "at home" rather than in a clinic. Communication is an important aspect of guest services and the cancer center program. Culturally sensitive care is offered, including a staff bilingual in English and Spanish.

The center's biggest challenge right now is community outreach. A full-time staff outreach person maintains contact with the local media, churches, medical centers, and physician practices in the community to get the word out about the cancer center and its services. Open houses are also held.

Already these outreach initiatives are paying off. Freeman noted that during cervical cancer awareness month, a local Spanish TV program featured a discussion on cervical cancer by one of the center's medical oncologists who is Latino. As a result, within a few days, the center received 80 phone calls for appointments for pap smears. A few weeks later, the same medical oncologist was again featured on the same Spanish TV program talking about colonoscopy. Some 150 people later called the center for appointments and the center provided these 150 people, who were uninsured, a colonoscopy paid for by public funds.

In addition, Freeman, who is also medical director of another breast cancer screening center in New York City, has trained the nurse practitioner to encourage patients age 50 and older who come in for a mammogram to consider being screened for colon cancer. In one year, said Freeman, about 600 women who came to the breast care center agreed to have a colonoscopy. Of that number, about half then came to the Ralph Lauren Center for consultation and colonoscopy screening. Five of those women actually were diagnosed with early colon cancer.

A challenge for the center in the years ahead, said Freeman, is "to diminish cancer morbidity and mortality, specifically breast and colon, in the Harlem community to numbers that are equal to the rest of the country." Freeman hopes that the Ralph Lauren Center will serve as a model and that the program might be duplicated for medically underserved populations in other areas of the country.

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Capital Breast Care Center in Southeast Washington, D.C.

In October 2003, a comprehensive breast cancer clinic for low-income residents in the southeast section of Washington, D.C., opened its doors thanks to a $1 million gift from the Avon Foundation. The center is a partnership between Georgetown University's Lombardi Comprehensive Cancer Center and MedStar Research Institute. The center's mission is to provide state-of-the-art breast healthcare to all women in the District of Columbia, through awareness, education, screening, and follow-up services.

The center helps fill a critical healthcare gap in the District of Columbia, said Jeanne Mandelblatt, MD, director of the Capital Breast Care Center in southeast Washington, D.C. Mandelblatt has been a long-time crusader to eliminate the disparity in access to quality medical care and treatment.

"We live in a city with the highest cancer mortality rate in the nation, and blacks suffer at a disproportionate level and have less access to treatment," said Mandelblatt, who is also director of cancer control at Lombardi Comprehensive Cancer Center. "We have a responsibility to give back to the community and make a difference."

The renovated 3,000-square-foot center offers a variety of breast health services for low-income residents. These comprehensive holistic services include patient clinical breast examinations, mammograms, patient education and counseling about breast cancer risk, counseling for women with a family history of breast cancer, and support and guidance from diagnosis through treatment.

During the first few months of operation, the center's van provided women with transportation back and forth from their homes or the center at either Washington Hospital Center or Georgetown University Hospital for mammography services "to try and overcome any barriers to access to care," Mandelblatt said. In April 2004, the center began providing mammography on site.

The center assures that all women are sent the results of their mammograms and that the patient's designated primary provider is also notified of the results. The information is entered into the center's database so that staff can track use, document follow-up, and send annual reminders to patients for repeat or annual screenings.

The center's services are available to *all* women who are residents in the District of Columbia. The center participates in a program that provides free services for women without insurance who live in the District. If a woman has insurance, the center accepts insurance assignment so that she doesn't have to pay out of pocket. "No one will be turned away," Mandelblatt said.

The center's multi-racial, bilingual staff includes a receptionist and biller, a health educator-navigator, nurse practitioners, a physician assistant, two physicians that serve as medical directors, and a project manager whose tasks range from coordinating community awareness efforts and the day-to-day operations of the center to working on philanthropic fundraising plus more. The center's health educator-navigator, who is familiar with the community and with the hospital system, ensures that women who need evaluation after an abnormal screening test receive prompt services to resolve the abnormality and get any necessary treatment.

Washington, D.C., mayor Anthony "Tony" Williams attends the October 2003 grand opening of the Capital Breast Care Center in southeast Washington, D.C.

While the center's primary focus now is on breast care, patients also receive blood pressure reading, are checked for their height and weight, and asked about their smoking history. Mandelblatt firmly believes that health education promotes lowering of cancer risk but also helps reduce other non-cancer disease risk factors, which overlap.

Raising community awareness and providing community education is also an important to the center. The Capital Breast Care Center hopes to serve between 4,000 and 6,000 patients—both new patients and follow-ups—over the next three years. Efforts to get the word out in both English and Spanish about the center's services have included local TV and radio coverage as well as coverage in the local print media, at community churches, community groups, and health fairs.

Once the center has established relationships with the local community and gained trust in the community, staff hopes to provide the community with access to clinical trials and research studies related to breast care.

"The Lombardi Comprehensive Cancer Center has made a commitment to make the Capital Breast Care Center a long-term service available to the community," said Mandelblatt, adding that she will be looking for additional organizations to partner with in the District of Columbia. "To address the pervasive cancer disparities in D.C. will take many partners working together to improve the situation," she said. Some of the community-based partners currently working with Mandelblatt include Zora Brown from the Breast Cancer Resource Committee and founder of *Rise, Sister, Rise*; Elmer Huerta, MD, MPH, from the Washington Hospital Center, and a network of special population clinics targeted to reach out to the Latino community as well as other community leaders.

References

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Marion Dinitz is a freelance healthcare writer in Rockville, Md.

A Rural Cancer Outreach Program in Virginia

by Mary Helen Hackney, MD

The Rural Cancer Outreach Program (RCOP) of the Virginia Commonwealth University Massey Cancer Center celebrated its 15-year anniversary in March 2004. The RCOP was developed in 1989 to bring state-of-the-art cancer care into medically underserved areas of Virginia. These areas had small hospitals with primary care physicians and general surgeons but limited numbers of or access to medical specialties, including oncology care.

The first goal of the RCOP was to provide state-of-the-art oncology care in the local communities. Additionally, the clinics would serve as conduits for patients who needed more specialized services or care better provided at a tertiary medical center. The developers of the RCOP also envisioned promoting cancer education and developing research activities within these regions.

The original four RCOP clinics are each located approximately 90 miles from the Massey Cancer Center in Richmond, Virginia. An associated clinic in Grundy, Virginia is approximately 350 miles away. The four larger clinics are located in small community hospitals (60-110 beds). Until the recent sale of one hospital, all were community not-for-profit hospitals. The local hospitals provide clinic space and clerical and nursing staff as well as laboratory, radiology, and pathology services. The Massey Cancer Center provides physicians and nurse practitioners. All chemotherapy billing goes to the hospital, and Massey Cancer Center providers bill *only* for evaluation and management (E&M) services.

The RCOP clinics are opened five days a week to provide chemotherapy and other supportive care. The Massey Cancer Center team of physicians and nurse practitioners visit each clinic two to three times per month to see patients. All patients must have a local primary care provider to assist with care in the absence of the Massey Cancer Center team. Providers see inpatient and outpatient consults, follow-up patients, and new patients for evaluation. Three of the sites are open for clinical trials available through the Massey Cancer Center research programs.

A radiation oncologist provides follow-up care and new patient evaluations once a month. Since there are no radiation oncology services in these communities, the Massey Cancer Center provides daily van transportation to radiation oncology treatment centers at Virginia Commonwealth University. Patients receiving other specialty care that cannot be executed in the local hospital (e.g., thoracic surgery procedures, bone marrow transplant, and Phase 1 clinical trials) must also travel to the Massey Cancer Center.

Nurse practitioners based at the Massey Cancer Center are the lynchpins ensuring smooth clinic operations. They are in daily contact with the rural clinic staff by telephone, fax, and email. These nurses provide guidance for patient triage and side effect management. They also provide continuing education for the nursing staff. The Massey Cancer Center physicians are available for phone consults, management questions, and medication orders.

While the RCOP program has grown beyond expectations, it is now threatened by increasing changes in healthcare reimbursements and costs. The business of medicine has changed, particularly with regards to billing and reimbursement.

As the costs of medications have risen and the reimbursement declined, balancing hospital budgets has not been easy. Because the RCOP hospitals are in rural areas, a significant number of Medicare and Medicaid patients are seen at these locations. Review of billing data from just the physician E&M charges showed up to 65 percent Medicare billing at one site.

Additionally, the RCOP treats a limited number of patients who have no insurance. The costs of treating these patients with chemotherapy strains a small hospital's budget. Unfortunately, pharmaceutical company support programs do not cover all of the costs of patient care and drug delivery, so many of the RCOP's most needy patients must travel to the Massey Cancer Center where limited state funds are available for indigent care.

Another area of concern is the high cost of chemotherapy drugs, which can undermine a small pharmacy. Due to their smaller drug volume usage, the small hospitals participating in the RCOP programs often cannot compete for the best price. The complexity of reimbursement can also lead to losses related to incomplete billing.

Physician and nurse practitioner billings do not support their salaries. The team travels by van to each site, and there is no reimbursement for travel time even if work is being done on the trip. The bottom line—the RCOP program does not exist without an influx of monies from the Massey Cancer Center.

Over the past decade, various oncology physicians have tried to establish practices in these rural sites independent of the Massey Cancer Center. One site has a private oncologist who sees patients twice a week with a similar setup to the RCOP. Other practices were started and then forced to close.

Most recently, one of the RCOP hospital sites has decided to reorganize oncology services. They have accepted a contract with a non-university group who will take over the buying, mixing, and distribution of chemotherapy, as well as patient care.

Although it is disappointing to close an RCOP clinic, the partnership relieves the hospital of the burden of rapidly escalating chemotherapy costs, as well as increases oncology services in the community by establishing a new practice.

The RCOP program has been successful as demonstrated by the large number of patients served and the program's longevity. The challenge now is to readjust the model under our ever-changing reimbursement climate so that rural Virginia cancer patients continue to have access to cutting-edge care.

Mary Helen Hackney, MD, is associate professor in the division of hematology/oncology at Virginia Commonwealth University.