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Abstract—Background. Profound advances in biomedical science have contributed to increased longevity and improved quality of life for many Americans. Despite this progress, a heavier burden of disease is borne by some population groups in the United States, particularly the poor and underserved. Landmark reports published since 1973 have highlighted these health disparities, explored their causal factors, and outlined strategies to reduce them. More recent research studies underscore the results of these early reports that identify social position, economic status, culture, and environment as critical determinants of who develops and survives cancer and of the quality of life of cancer survivors. Methods. The Patient Navigation Program was established in Harlem, New York, in 1990 to address the dramatic disparities in breast cancer mortality among minority women in the community. Results and Conclusions. The success of the Harlem Patient Navigation Program has provided the impetus for the development of many similar patient navigation programs across the country and for federal support for Patient Navigation research to address the critical need for effective interventions to eliminate cancer health disparities, particularly among minorities and the underserved. J Cancer Educ. 2006; 21(Suppl.):S11-S14.

There is a critical disconnect between what we discover in cancer research and what we deliver to all American people. This “discovery to delivery” disconnect is a key determinant of the unequal burden of cancer (Figure 1).1

BACKGROUND

The Origin and Evolution of the Patient Navigator Program

In 1989, in my role as President of the American Cancer Society (ACS), I conducted a series of hearings throughout the country to hear the testimony of poor Americans who had been diagnosed with cancer. Based on these hearings, ACS issued “Cancer and the Poor: A Report to the Nation” in 1989.2 In their report, the ACS identified the most critical issues related to cancer in the poor as follows:2

1. Poor people meet significant barriers when they attempt to seek diagnosis and treatment of cancer.
2. Poor people and their families make sacrifices to obtain cancer care and often do not seek care because of the barriers faced.
3. Poor people also experience more pain, suffering, and death because of late diagnosis and treatment at an incurable stage of the disease.
4. Fatalism about cancer is prevalent among the poor and prevents them from seeking care.

As a result, the ACS supported the nation’s first “Patient Navigation” program, established in 1990 at the Harlem Hospital Center.

The Patient Navigation Model: Navigating a Patient Through the Complex Health Care Delivery System

A critical window of opportunity exists to save lives from cancer between identification of an initial suspicious finding and resolution of a cancer diagnosis through treatment. The Patient Navigator Model promotes access to timely cancer diagnosis and treatment and aims to ensure seamless, coordinated care and services by assisting cancer patients and their families in “navigating” through our complex health care delivery system (Figure 2).3

Patient Navigators must be trained to be knowledgeable of the local environment and be familiar with the complexities of the system through which patients must move to obtain timely and adequate diagnosis and treatment. Although no particular level of formal education is required to be a Patient Navigator, it is critical that Patient Navigators be culturally attuned and able to communicate effectively with the patient community they serve and show sensitivity and compassion to the patients and their families whom they assist in navigating the health care system. It is also imperative that Patient...
Navigators be connected to decision makers within the healthcare system, especially the financial decision makers.

Community Demographics: Central Harlem and East Harlem

Central and East Harlem are populated predominantly by people of African American and Latino/Hispanic descent. Many residents live in poverty and have a low level of education. In 1990, McCord and I reported in the New England Journal of Medicine that a Black male in Harlem had less of a chance of reaching age 65 than a male in Bangladesh, a fact that persists to this day.

In Central Harlem, the population is predominantly African American (67%), with a median household income of $22,367 per year. Approximately 47% of the population have completed high school, but only 17% of the population has earned a high school diploma; 8% of the population have completed 4 or more years of college.

Latinos/Hispanics are the largest ethnicity (55%) in East Harlem, predominantly of Puerto Rican descent (51.8%). Other ethnicities represented in this community are Mexican (9%), Dominican (5%), Central American (3%), and Ecuadorian (1%). The median household income is $23,309 per year. The median years of school completed is 11 years, with 30% completing less than high school and 31% completing high school without earning a diploma. Approximately 22% of the community holds a high school diploma, 13% have completed some college, and approximately 5% have completed 4 or more years of college.

RESULTS

Harlem Hospital Cancer Control Center Screening and Patient Navigation Program

Breast cancer is the second leading cause of female cancer deaths in the United States. Late diagnosis and treatment at
an incurable stage of the disease is the principal cause of mortality, totaling greater than 40,400 US female cancer deaths annually.\textsuperscript{7}

In the 22-year period from 1964 to 1986, 606 female breast cancer patients (of which 94\% were African American) were treated at Harlem Hospital in New York. Nearly all of these patients were poor, 50\% were medically uninsured, and nearly half were incurable at diagnosis. In an initial study of this patient population, only 6\% were diagnosed with early stage breast cancer (when the disease is most curable), whereas 94\% were diagnosed at later stages of disease. In the most extreme cases, we saw the breast totally replaced by the cancerous tumor. Not surprisingly, the 5-year survival rate for these patients was 39\% compared to greater than 60\% in US White women during that period.\textsuperscript{8}

Prior to a follow-up study, the Harlem Hospital Cancer Control Center instituted programs to provide free and low-cost screening mammography services and established a Patient Navigation program to navigate patients through the complex health care system to access cancer care without delay from screening through to resolution. In addition, the Center strengthened and expanded its community outreach and public education programs on primary and secondary cancer prevention strategies. In poor communities such as Harlem, we found that it is imperative to ensure screening and treatment services are available \textit{before} educating the community to seek these services.

In a subsequent study conducted from 1995 to 2000 and reported in the \textit{Journal of the American College of Surgeons},\textsuperscript{9} a total of 324 patients with breast cancer—70\% African American and 26\% Latina/Hispanic—were diagnosed and treated at the Harlem Hospital Cancer Control Center. Approximately half of these patients were uninsured, and nearly all were poor. The impact of the Harlem Hospital Center’s Breast Cancer Screening and Patient Navigator Programs on stage at diagnosis and 5-year survival is shown in Figures 3 and 4, respectively.

Results of the second study\textsuperscript{9} showed dramatic improvements in the number of patients diagnosed at earlier stages of breast cancer and a dramatic increase in breast cancer survival rates among patients treated at the Harlem Hospital Center. Comparisons of the two studies show that 41\% of breast cancer patients were diagnosed at early stages of disease,\textsuperscript{9} as opposed to only 6\% of patients in the earlier study.\textsuperscript{8} Improvements in 5-year survival rates also increased dramatically from 39\% in the early study\textsuperscript{8} compared to 70\% in the follow-up study.\textsuperscript{9}
FINAL THOUGHTS

In communities of low socioeconomic status, patient navigation has proved to be an effective intervention in promoting screening, timely diagnosis, and treatment of cancer. Three major factors to improve cancer outcome are:

- Provide screening to patients regardless of ability to pay,
- Establish patient navigation program to eliminate any barrier to screening and timely diagnosis and treatment, and
- Increase outreach and public education.

The evidence is now clear that many people living in the United States do not have access to adequate and timely cancer primary and secondary prevention information and detection services, nor do they receive the most appropriate care when faced with a diagnosis of cancer. Throughout our deliberations in 2000 and 2001, the President’s Cancer Panel heard a common theme echoed in the testimony given by over 350 cancer patients, survivors, and their families as well as oncologists, cancer surgeons and other medical personnel, hospital administrators, and other cancer advocates: that no person battling cancer in the United States should go untreated or experience delays in diagnosis and treatment that jeopardize their survival, and no person or family in the United States should be bankrupted by a diagnosis of cancer.

The war on cancer has not been fought equitably on all fronts. To win the war against cancer, we must tear down the economic, cultural, and societal barriers to cancer prevention, early detection, diagnosis, and treatment; and we must eliminate all cancer health disparities.

Patient Navigation programs throughout the nation could help to close the “disconnect” between what we have discovered through research and what we deliver to all our citizenry. We must apply what we know at any given time to all people, with the goal of having everyone share in the benefits of advances in cancer research.

References
