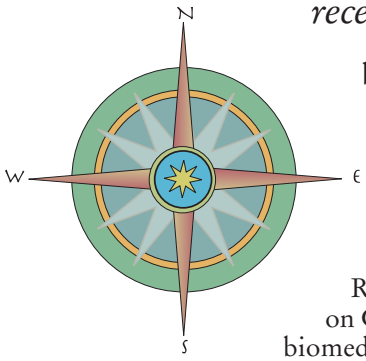
A Model Patient Navigation Program

Breaking down barriers to ensure that all *individuals with cancer receive timely diagnosis and treatment*

by Harold P. Freeman, MD



Since 1971, when President Richard Nixon declared a "War on Cancer," profound advances in biomedical science, especially at the molecular/genetic level, have increased longevity and improved quality of life for many patients. Despite our tremendous scientific advances, some populations in this country bear a heavier burden of cancer, particularly the poor and underserved, as evidenced by their high cancer incidence, mortality, and lower survival. Over the last three decades, a number of landmark reports have been published that identify health disparities as an important national concern.

Disease always occurs within a context of human circumstances including economic status, social position, culture, and environment. These human circumstances can determine length and quality of survival. The existence of health disparities poses a challenge to the scientific community and is a moral and ethical dilemma for this nation. A significant disconnect exists between what we discover and what we deliver to all people. This disconnect is, in and of itself, a cause of disparities.

Understanding Health Disparities

The three principal causes of health disparities are poverty/low economic status, culture, and social injustice. These complex, extremely powerful factors are strong determinants of the length and quality of survival of individuals with cancer.[1]

Of these three causes, poverty has the greatest overall impact on the existence of health disparities. Poverty is characterized by substandard housing, inadequate information and knowledge, risk-promoting lifestyles, attitudes and behaviors, and diminished access to healthcare.

Culture, a second factor, embodies shared communication systems, similar physical and social environments, common beliefs, values, traditions, and world views, and similar lifestyles, attitudes and behaviors. Culture may augment or diminish poverty's expected negative effects.

The third factor, social injustice, is also critical in creating and maintaining health disparities, particularly among racial and ethnic minority populations. Race is the single most defining issue in the history of American society. In our society, we see, value, and behave toward one another through a powerful lens of "race."[2] This lens can create false assumptions that may result in serious harm to members of some racial and ethnic groups. For example, the Institute of Medicine (IOM) determined that currently African Americans are less likely to receive standard treatments for cancer even at the same insurance and economic status.[3]

An understanding of this complex and overlapping interplay of poverty, culture, and social injustice underscores the challenge of reducing cancer disparities and could lead to strategies to eliminate these disparities.

The Origin of Patient Navigation

In 1989, as President of the American Cancer Society (ACS), I conducted a series of hearings throughout America to hear the testimony of poor Americans who had been diagnosed with cancer. Based on these hearings, the ACS issued its *Report to the Nation on Cancer in the Poor in 1989*. The report found the four most critical issues related to cancer in the poor to be:

1. Poor people meet significant barriers when they attempt to seek diagnosis and treatment of cancer.
2. Poor people and their families make sacrifices in order to obtain cancer care and often do not seek care because of barriers faced.
3. Poor people 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.

In part because of these findings, the first Patient Navigation program was conceived and initiated in 1990 at Harlem Hospital Center in New York City, funded by an ACS grant. While the model program was based on an experience with breast cancer, patient navigation can be applied to the diagnosis and treatment of all cancers and possibly other diseases.[4]

Goals of Patient Navigation

To save lives from cancer, we must first provide outreach and education programs that inform women about the need for breast examination. Second, we must provide access to breast examinations, including screening mammography, to all women. Lastly, we must ensure that any woman with a positive finding will receive further diagnosis and treatment on a timely basis.

There is a particularly critical window of opportunity to save lives from cancer between a point of a suspicious finding and the resolution of the finding by further

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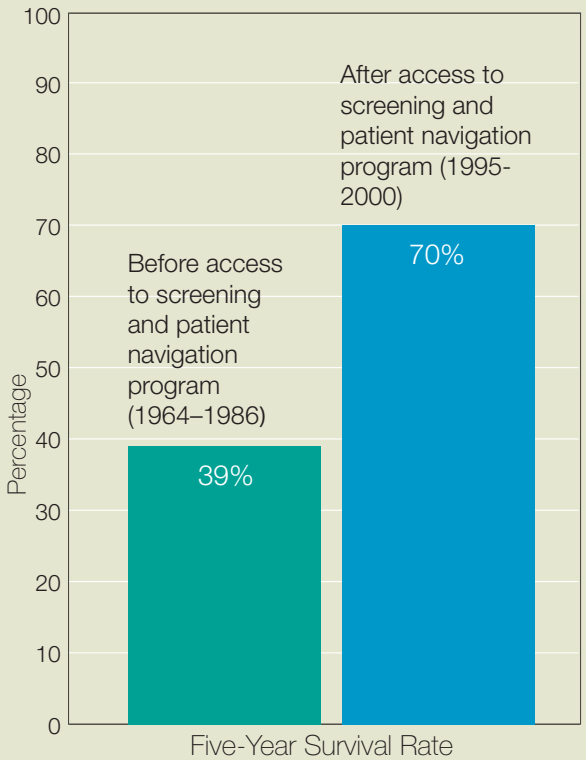
Table 1: Impact of Harlem Hospital Center Breast Cancer Screening and Patient Navigation Program



Source: *Cancer* 1989. Source: *Journal of American College of Surgeons* 2003.

diagnosis and treatment. Many barriers may be experienced during this interval including financial barriers (i.e., the uninsured and underinsured); communication and information barriers; medical system barriers (i.e., missed appointments and lost results); and fear and emotional barriers.

The most important role of Patient Navigation is to assure that an individual with a suspicious cancer-related finding will receive timely diagnosis and treatment. The Navigator accomplishes this most effectively through one-on-one contact with the patient beginning at the point of a positive finding. This process is intended to eliminate barriers to diagnosis and treatment. While no particular level of formal education is required of a Patient Navigator, a successful candidate should be:

- Culturally attuned to the people of the community being served, able to communicate, be sensitive and compassionate.
- Very knowledgeable about the environment and system through which the patient must move in order to obtain care.
- Highly connected and allied with critical decision makers within the system, especially with the financial decision makers.

The Harlem Experience

Harlem is a community of predominantly African Americans and Hispanics. Many residents live in poverty with a low level of education. In 1990 *The New England Journal of Medicine* reported that a black male in Harlem has less of a chance of reaching age 65 than a male in Bangladesh.[5] This fact persists to this day.

Breast cancer is the second leading cause of cancer deaths in women, claiming the lives of more than 40,000 women in this country each year. Late diagnosis and treatment at an incurable stage of the disease is the principal cause of death.

In a 22-year period ending in 1986, 606 patients (94 percent black) with breast cancer were treated at Harlem Hospital Center. Almost all patients were of low-economic status and almost 50 percent had no medical coverage. Nearly half were incurable at diagnosis (Stages 3 and 4) and only 6 percent had early breast cancer (Stage 1 disease). The five-year survival rate of these patients was 39 percent compared to more than 60 percent in American white women at that time.[6]

In a separate study, which was recently published in the *Journal of the American College of Surgeons*, 324

Patient Navigation...
has great potential to *save lives...*

patients with breast cancer were diagnosed and treated at the Harlem Hospital Cancer Control Center between 1995-2000. Of these patients, 70 percent were black and 26 percent, Hispanic. Nearly half of these patients had no medical insurance on initial evaluation. This study showed dramatic improvements in staging and five-year survival rates. The results were: 41 percent, Stages 0 and 1, and only 21 percent, Stages 3 and 4. The five-year survival, which could be determined for 76 patients, was 70 percent compared to 39 percent in the previous Harlem Hospital Study[7] (see Table 1).

Three major factors accounted for the dramatically improved results demonstrated in the recent Harlem experience. First, the center offered free and low-cost screening mammography, which allowed for early diagnosis. Second, the Patient Navigation program promoted treatment with no delay. Finally, the improved outreach and public education were believed to have played an important role in the new findings.

Food for Thought

In 2001 the President's Cancer Panel issued a report to President George W. Bush titled *Voices of a Broken System* based on the testimony of Americans who sought treatment for cancer. The report indicated that barriers to obtaining cancer care exist for people at all socioeconomic levels. One of the panel's principle recommendations was that funding should be provided to help communities coordinate, promote, and support community-based programs, including Patient Navigation programs, to help people obtain cancer information, screening, treatment, and supportive services.

The report revealed three important conclusions:

- No person with cancer should go untreated
- No person with cancer should be bankrupted by a diagnosis of cancer
- No person with cancer should be forced to spend more time fighting their way through the healthcare system than fighting their disease.[8]

The Patient Navigation program offers a support system for people helping people, alleviating the burden of patients seeking care in a "broken" healthcare system. These programs are developing in communities throughout America, and general application of this initiative has the potential to save many lives.

The concept of Patient Navigation is even receiving attention at the national level. In February 2003 Representatives Robert Menendez (D-N.J.) and Deborah Pryce (R-Ohio) introduced legislation (H.R. 918) in the House, and Senators Kay Bailey Hutchinson (R-Texas) and Jeff Bingamen (D-N.M.) introduced a companion bill (S. 453) in the Senate to create Patient Navigation programs to help individuals seek affordable and accessible prevention, detection, and treatment services for cancer. Agencies in the Department of Health and Human Services are also examining the effectiveness of Patient Navigation programs through pilot studies.

The war against cancer has not been fought equitably on all fronts. To win this war, we must apply what we know at any given time to all people, and we must also recognize and eliminate all barriers to quality cancer care. Patient navigation is one community intervention that has great potential to save lives by eliminating economic and cultural barriers to the early diagnosis and treatment of cancer.

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