

## The Origin, Evolution, and Principles of Patient Navigation

Harold P. Freeman

This issue of *CEBP* focuses on patient navigation with specific emphasis on the findings of the National Cancer Institute (NCI) Patient Navigation Research Program (PNRP). This research program was designed to develop interventions to reduce the time to diagnosis and treatment of cancer after identifying an abnormal finding from a cancer detection procedure. The basic goal of navigation is to facilitate timely access for all to quality standard care in a culturally sensitive manner. The concept for the NCI Patient Navigation Research Program was derived primarily from the original patient navigation concept and model, which was pioneered by Harold P. Freeman in Harlem, New York (1).

The results of the NCI PNRP studies are well summarized by Byers in this issue of *CEBP*. The weight of evidence from the PNRP studies indicates that patient navigation can reduce the time from abnormal findings to diagnosis in breast, cervix, colorectal, and prostate cancer (2).

Previous studies had already shown that patient navigation can increase participation in screening (3). Therefore, the sum of net benefits from patient navigation seems to be considerable. Current evidence suggests that patient navigation will be most beneficial to those at high risk for late diagnosis, such as the poor and uninsured. With respect to cost effectiveness, I agree with Byer's conclusion that it is likely that the modest cost of navigation will be easily offset by savings due to stage shifts that will result in the avoidance of the high costs of treating advanced cancer.

The goal of this editorial is to place patient navigation in historical perspective, discuss the philosophy and principles of patient navigation, and show how this relatively new health care delivery support strategy has evolved since its inception in 1990.

### The History of Patient Navigation

Patient navigation has evolved as a strategy to improve outcome in vulnerable populations by eliminating barriers to timely diagnosis and treatment of cancer and other chronic diseases. In 1989, the American Cancer Society held "National Hearings on Cancer in the Poor". The hearings were led by the President of the

Society and were conducted in seven American cities. The testimony was primarily by poor Americans of all racial and ethnic groups who had been diagnosed with cancer. On the basis of these hearings, the American Cancer Society issued its "Report to the Nation on Cancer in the Poor" (4).

The report concluded that the most critical issues confronting poor people with cancer are as follows:

- Poor people face substantial barriers to obtaining cancer care and often do not seek care if they cannot pay for it.
- Poor people and their families often make extreme personal sacrifices to obtain and pay for care.
- Fatalism about cancer is prevalent among the poor and may prevent them from seeking care.
- Cancer education programs are often culturally insensitive and irrelevant to many poor people.
- Poor people endure greater pain and suffering from cancer than other Americans.

These findings led to the concept of patient navigation. The nation's first patient navigation program was initiated by Freeman in 1990 at a public hospital in Harlem, New York. The original program focused on the critical window of opportunity to save lives from cancer by eliminating barriers to timely care between the point of suspicious finding and the resolution of the finding by diagnosis and treatment. The aim was to diminish the extremely high breast cancer death rate in a population of poor black women, half of whom had presented with late-stage breast cancer.

Commonly experienced barriers to timely care in Harlem were:

- Financial barriers, such as no health insurance
- Communication and information barriers
- Medical system barriers
- Fear, distrust, and emotional barriers.

Subsequently, the scope of patient navigation was expanded to be applied across the entire health care continuum, including prevention, detection, diagnosis, treatment and survivorship to the end of life (Fig. 1). Retrospective studies of the Harlem hospital breast cancer experience showed that the combined interventions of patient navigation and free or low cost breast cancer screening resulted in a significantly increase in early-stage cancer diagnosis and treatment and marked increased 5-year survival (39%–70%) in a population of all poor and half uninsured black women (5, 6).

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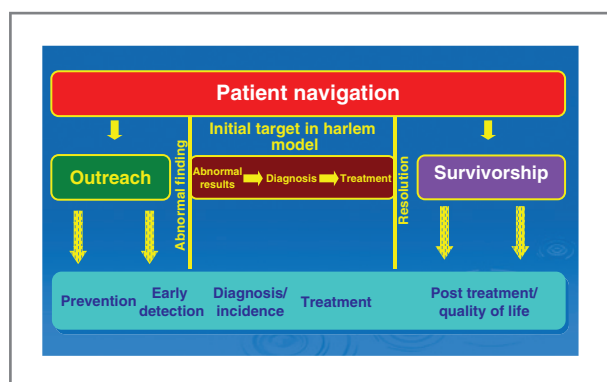


Figure 1. Expanded model. Reprinted from DeVita et al. (11); with permission.

### Funding for Patient Navigation Research and Programs

Over the past decade, the federal government has provided significant funding for patient navigation research. Research has been supported by the National Cancer Institute the Center's for Medicare and Medicaid Services (CMS), the Center for Disease Control and the Health Resources and Services Administration (HRSA). In 2005, President George Bush signed the Patient Navigator and Chronic Disease Prevention Act. This legislation provided funding to HRSA for patient navigation demonstration research. In 2012, the American College of Surgeons Commission on Cancer mandated that Patient Navigation is to be a standard of care to be met by cancer programs seeking approval beginning in the year 2015. The Affordable Care Act (ACA) includes references to patient navigation. The ACA requires that states establish exchanges to facilitate access to health insurance coverage for individuals. The ACA also requires that each state health insurance exchange establish a "navigator program" to help individuals make informed decisions about enrolling in health insurance through the exchange. The ACA extends the length of the Patient Navigator and Chronic Disease Prevention Act grant program to 2015. In 2012, the Patient Navigation Assistance Act is being introduced into the Congress. The intent of this Act is to provide medicaid coverage for patient navigator services.

In addition to federally sponsored programs, patient navigation has been supported by a number of non-government organizations including the American Cancer Society, the Komen Foundation, the Lance Armstrong Foundation, Avon, Pfizer, and Accenture Foundation.

### The Discovery/Delivery Disconnect

In 1971, President Richard Nixon signed the National Cancer Act and declared a "war on cancer." This resulted in a significant increase in the nation's invest-

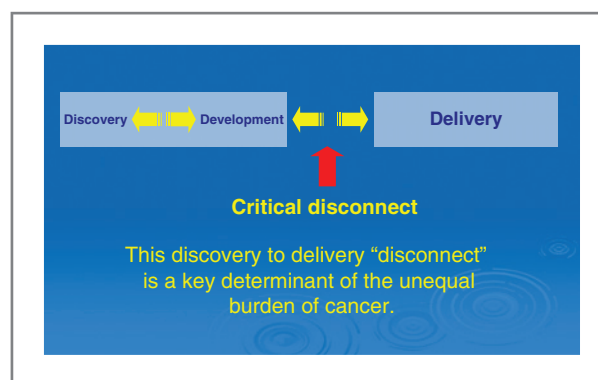


Figure 2. The discovery-delivery disconnect. Reprinted from Freeman (10); with permission.

ment in cancer research. In the decades since this declaration, the nation has made extraordinary progress toward a more in depth understanding of the molecular, cellular, and genetic changes resulting in cancer. We have also seen significant declines in overall and site-specific cancer mortality (7). This decline in mortality has been attributed to improved cancer prevention, screening and detection measures, as well as application of more effective cancer treatments. However, some Americans, in particular the poor, the uninsured, and the underinsured, have not fully benefited from this progress as measured by higher cancer mortality and lower cancer survival. Poor and uninsured Americans meet significant barriers to obtaining timely diagnosis and treatment of cancer and other life threatening diseases. Such barriers lead to late diagnosis and treatment and increased mortality. These findings suggest that there is a disconnect between the nation's discovery and delivery enterprises; a disconnect between what we know and what we do (Fig. 2).

This discovery/delivery disconnect is believed to be a principal determinant of the unequal burden of cancer and resultant cancer health disparities. Another way of stating this is that disparities result when proven educational and medical interventions are not shared by all. The unequal burden of cancer is a challenge to science and, more importantly, a moral and ethical dilemma for this nation.

### The Poor and Uninsured

It is like a tale of two cities. The American health care system offers the very best care to many. But, poor and uninsured Americans typically have low access to timely health care even when faced with a life threatening disease such as cancer. According to the 2010 US Census Bureau report, in 2009, there were 43.6 million or 14.3% poor Americans (8). A disproportionate percentage of African Americans (25%) and Hispanic Americans (25%) live below the poverty line. In the same year (2010), an estimated 50 million Americans (16%) were

without health insurance coverage. Note that 32% of Hispanics, 21% of blacks, and 12% of whites are uninsured. Note also that half of the uninsured and nearly half of poor Americans are white (8). Poor and uninsured Americans are more likely to be diagnosed with late-stage cancer and are more likely to die from the disease. Poverty is associated with low educational level, substandard living conditions, inadequate social support, unemployment, risk promoting life style, and diminished access to timely health care.

### The Principles of Patient Navigation

The momentum that patient navigation has received as a community-based intervention (which has expanded and been transformed into a nationally recognized model) has stimulated the need to define principles and standards for patient navigation. Below are listed the Principles of Patient Navigation that have been developed and vetted for more than 20 years through the author's experience (9).

1. Patient navigation is a patient-centered health care service delivery model. The focus of navigation is to promote the timely movement of an individual patient through an often complex health care continuum. An individual's journey through this continuum begins in the neighborhood where he or she lives, to a medical setting where an abnormality is detected, a diagnosis is made, and then treatment rendered. The journey continues from rehabilitation and survivorship to the end of life.
2. Patient navigation serves to virtually integrate a fragmented health care system for the individual patient. As patient care is so often delivered in a fragmented manner, particularly related to those with chronic diseases, patient navigation has the potential of creating a seamless flow for patients as they journey through the care continuum. Patient navigation can be seen as the guiding force promoting the timely movement of the patient through a complex system of care.
3. The core function of patient navigation is the elimination of barriers to timely care across all phases of the health care continuum. This function is most effectively carried out through a one-on-one relationship between the navigator and the patient.
4. Patient navigation should be defined with a clear scope of practice that distinguishes the role and responsibilities of the navigator from that of all other providers. Navigators should be integrated into the health care team to promote maximum benefit for the individual patient.
5. Delivery of patient navigation services should be cost-effective and commensurate with the training and skill necessary to navigate an individual through a particular phase of the care continuum.
6. The determination of who should navigate should be based on the level of skill required at a given phase of

navigation. There is a spectrum of navigation extending from services that may be provided by trained lay navigators to services that require navigators who are professionals, such as nurses and social workers. Another consideration to take into account is that health care providers should ideally provide patient care that requires their level of education and experience and should not be assigned to duties that do not require their level of skills.

7. In a given system of care there is the need to define the point at which navigation begins and the point and which navigation ends.
8. There is a need to navigate patients across disconnected systems of care, such as primary care sites and tertiary care sites. Patient Navigation can serve as the process that connects disconnected health care systems.
9. Patient Navigation systems require coordination. In larger systems of patient care, this coordination is best carried out by assigning a navigation coordinator or champion who is responsible for overseeing all phases of navigation activity within a given health care site or system. It is important to distinguish a system of patient navigation from the patient navigator(s) who work within the system.

### Final Thoughts

From its origin in Harlem about 2 decades ago, patient navigation has rapidly expanded and has become a nationally recognized health care service delivery model. Key markers of this progress are as follows: the American College of Surgeons has designated the patient navigation process as a standard of care to be met by cancer centers seeking approval by the College. Also, the Affordable Care Act includes patient navigation requirements.

The nation faces a severe health care challenge. The 50 million uninsured and the overlapping 46 million poor Americans, in particular, lack access to timely diagnosis and treatment of cancer and are therefore frequently diagnosed with late stage disease. Patient navigation has been shown to improve cancer outcome in the poor and uninsured.

The philosophy of patient navigation encourages a system of health care delivery, which supports timely movement of the individual patient through an often complex and fragmented health care system. Patient navigators can also serve to connect systems of care for individual patients by applying the core function of navigation, which is the elimination of barriers to timely care across all segments of the health care continuum.

I believe, we must declare a new kind of war against cancer... a guerrilla war to tear down the economic and cultural barriers to prevention, early detection, and treatment of cancer. This hand to hand combat must

be carried out in the neighborhoods of America where people live and, too often, die. The results of the NCI Patient Navigation Research Program, published in this issue of *CEBP* add considerably to the increasing weight of evidence which indicates that patient navigation has the potential of substantially assisting in this ground war as an effective approach to improving access to life-saving health care, especially for the

poor, the uninsured, and other medically underserved Americans.

#### Disclosure of Potential Conflicts of Interest

No potential conflicts of interest were disclosed.

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