

History and Principles of Patient Navigation*

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In 1971, President Richard Nixon declared a war on cancer and signed the National Cancer Act. During the past several 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.¹ This decline in mortality has been attributed to improved cancer prevention, screening, and detection measures as well as the application of more effective and more targeted cancer treatments.

However, some Americans (such as the poor, uninsured, and underinsured) have not shared sufficiently in this progress as measured by higher mortality and lower 5-year cancer survival.²⁻⁴ 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 for all people (Fig. 1). Disparities occur when beneficial medical interventions are not shared equally by all. Moreover, health disparities arise from a complex interplay of economic, social, and cultural factors. The model presented in Figure 2 illustrates the overlapping factors of poverty, culture, and social injustice as principal causes of health disparities.⁵ These causal factors impact on all aspects of the healthcare continuum from prevention, detection, diagnosis, treatment, and survival to the end of life. Disparities occur principally in individuals or populations who experience one or more of the following circumstances: insufficient resources, risk-promoting lifestyle and behavior, and social inequities. Approaches to reducing or eliminating disparities must take these factors into consideration.

POVERTY AS A CAUSE OF CANCER DISPARITIES

Poverty is associated with low educational level, substandard living conditions, inadequate social support, unemployment, risk-promoting lifestyle, and diminished access to health care. According to the 2010 US Census Bureau report, in 2009 there were 43.6 million Americans (14.3%) classified as poor. This represents an increase of 4 million poor Americans compared with 2008. The overall 5-year survival for all cancers combined is 10% lower in the poor than in more affluent Americans. Additionally in 2009, an estimated 50.7 million Americans (16.7%) were without health insurance coverage.

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. The development of the concept of patient navigation was related to the findings of the *American Cancer Society National Hearings on Cancer in the Poor*. The hearings were conducted in 1989 in 7 American cities. The testimony was primarily by poor Americans of all races and ethnic groups who had been diagnosed with cancer.

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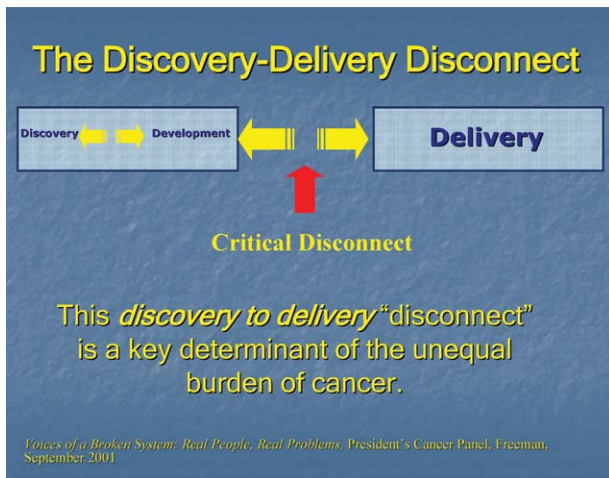


Figure 1. Discovery-delivery disconnect.

Based on these hearings, the American Cancer Society issued a “Report to the Nation on Cancer in the Poor” in 1989. The report found that the most critical issues related to cancer and the poor 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 endure greater pain and suffering from cancer than other Americans.
- Poor people and their families often make extraordinary personal sacrifices to obtain and pay for care.
- Fatalism about cancer is prevalent among the poor and may prevent them from seeking care.
- Current cancer education programs are often culturally insensitive and irrelevant to many poor people.

Related to these findings, the nation’s first patient navigation program was conceived and initiated in 1990 in Harlem, New York, by Dr. Harold Freeman.

This original program focused on the critical window of opportunity to save lives from cancer by eliminating barriers to timely care between the point of a suspicious finding and the resolution of the finding by further diagnosis and treatment.⁶

Commonly experienced barriers to timely care in the Harlem study were as follows:

- 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 (Fig. 3) has been expanded to be applied across the entire healthcare

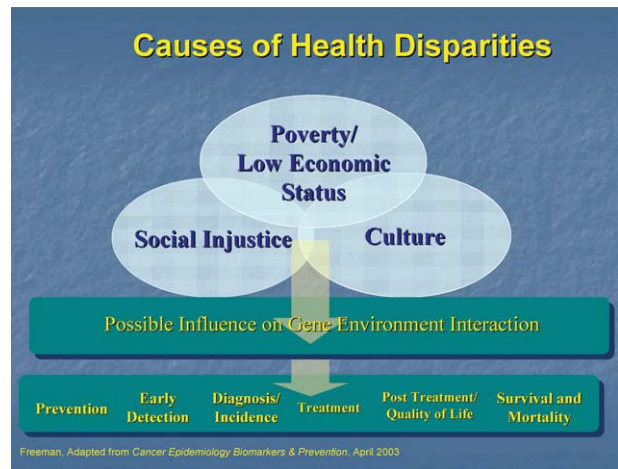


Figure 2. Causes of health disparities.

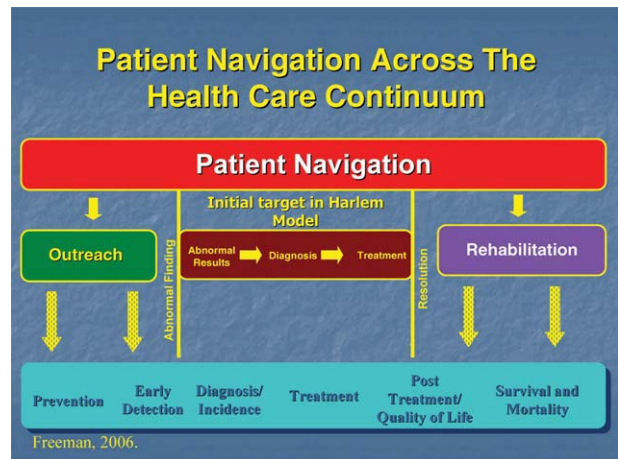


Figure 3. Current patient navigation model.

continuum, including prevention, detection, diagnosis, treatment, and survivorship to the end of life.

THE HARLEM BREAST CANCER EXPERIENCE

Before intervention, in a 22-year period ending in 1986, 606 patients (94% black) with breast cancer were treated at Harlem Hospital Center in New York City. All patients were of low economic status, and half had no medical insurance on initial visit. The results were as follows: only 6% of these patients had stage 1 disease, 49% presented with stage 3 and 4 disease. The 5-year survival rate was 39%.⁷

After intervention the results were dramatically improved. The intervention consisted of 2 elements: providing free and low-cost examinations/mammograms,

according to recommended guidelines, and patient navigation to ensure that all patients received timely diagnosis and treatment. The results were as follows: of 325 breast cancer patients, 41% of patients had early breast cancer (stage 0 and 1), 21% of patients had stage 3 and 4 disease. The 5-year survival was 70%.⁸

Two major factors are believed to account for these dramatically improved results achieved in a population of disproportionately poor and uninsured patients in Harlem: providing free/low-cost breast examinations, which led to early detection of abnormal finding; and patient navigation, which ensured timely diagnosis and treatment.

Based principally on the patient navigation model in Harlem, the Patient Navigator and Chronic Disease Prevention Act (HR 1812) was passed by Congress and signed into law by President Bush in 2005.⁹ To date, more than 20 patient navigation demonstration sites have been funded by 4 different government agencies. The American College of Surgeons (ACoS) has determined that patient navigation will soon be a required standard for cancer center approval by the ACoS Commission on Cancer.

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.

1. *Patient navigation is a patient-centric healthcare service delivery model.* The focus of navigation is to promote the timely movement of an individual patient through an often complex healthcare 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 healthcare 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 segments of the healthcare 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 healthcare 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 skills necessary to navigate an individual through a particular phase of the care continuum.*
6. *The determination of who should navigate should be determined by the level of skills 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 healthcare 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 at 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 healthcare 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 healthcare 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

Health disparities are caused by a complex interplay of low economic status, culture and social injustice, with poverty playing the dominant role. There is a critical disconnect between what we discover and what we deliver to all Americans in the form of prevention, diagnosis, and treatment of cancer and other diseases. This disconnect between what we know and what we do is a major determinant of health disparities.

Many patients, especially the poor, uninsured, and those who are culturally different, meet significant barriers to obtaining timely health care. These barriers include, but are not limited to financial, communication, medical system, transportation, and emotional barriers.

Patient navigation is a healthcare delivery support system with the principle function of eliminating barriers to timely delivery of health care for individual patients across the healthcare continuum. Patient navigators may be assigned specific phases of the patient navigation model, which may include prevention, detection, diagnosis, treatment, and survivorship through the end of life. In larger systems of health care, there is a need to oversee and coordinate the various phases of activity of patient navigators across the healthcare continuum.

Since its origin in Harlem in 1990, the concept of patient navigation has been widely adopted and applied in various forms at hundreds of healthcare sites throughout the country as well as abroad. Of particular significance is the fact that 4 separate government agencies have initiated patient navigation demonstration programs.

As an emerging healthcare intervention, patient navigation has the potential to significantly improve timely

access to diagnosis and treatment and thereby to improve survival and quality of life especially for the nation's most vulnerable populations.

No patient with cancer should go untreated. No patient with cancer should experience a delay in treatment that diminishes survival. No patient should be bankrupted by the diagnosis and treatment of cancer.¹⁰

CONFLICT OF INTEREST DISCLOSURES

The authors made no disclosures.

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