

# Virtual Mentor

American Medical Association Journal of Ethics  
November 2006, Volume 8, Number 11: 762-765.

## Policy forum

### Health communication and navigating the health system

by Andrea M. Garcia, JD

When the Office of Disease Prevention and Health Promotion, located within the Department of Health and Human Services (DHHS), released its Healthy People 2010 goals, “health communication” was listed as one of the new focus areas, making better communication one of the nation’s top health objectives [1]. The 2004 Institute of Medicine Report on Health Literacy stated that “clear communication is critical to successful health care” [2]. Unfortunately, within the current health care system those with the greatest burdens often have the least access to information and services.

Limited ability to read and understand health information makes it difficult to navigate the health care system and appears to contribute to health disparities [3]. In the United States about 90 million or 47 percent of adults have limited literacy skills [4]. According to the Health Resources and Services Administration (HRSA) limited health literacy is more prevalent among older adults, minority populations, the poor and the medically underserved [5]. Poverty has also been shown to be intertwined with many sociodemographic variables, which in turn are associated with limited literacy [6].

Fifteen years prior to the Institute of Medicine’s report on health literacy, the American Cancer Society in coordination with the National Cancer Institute and the Centers for Disease Control conducted fact-finding hearings to better understand the experiences of poor Americans who had been diagnosed with cancer [7]. Based on testimony heard during these hearings, the American Cancer Society issued “Cancer in the Poor: A Report to the Nation” [8]. The report’s findings suggested that:

- Poor people lack access to quality health care and are more likely than others to die of cancer.
- Poor people endure greater pain and suffering from cancer than most Americans.
- Poor people face substantial obstacles to obtaining and using health insurance and often do not seek needed care if they cannot pay for it.
- Poor people and their families must make extraordinary personal sacrifices to obtain and pay for health care.
- Cancer education and outreach efforts are insensitive and irrelevant to many poor people.

- Fatalism about cancer among the poor prevents them from gaining quality health care [7].

These findings led Harold P. Freeman to start one of the country's first patient navigator programs at Harlem Hospital Center in New York City in 1990. A patient navigator is defined as "someone who helps assist patients overcome barriers to care" [9]. Patient navigators provide individualized assistance such as coordinating appointments, maintaining communication to monitor satisfaction, helping patients understand medical jargon, arranging language translation, facilitating financial support, planning transportation or child care and establishing linkages for follow-up services [10]. Freeman's program demonstrated that those who received these services, primarily low income and medically underserved patients, had a significantly shorter time until follow-up services were received than those who did not have access to these services [11]. Similarly, a later study at Harlem Hospital attributed significant improvements in diagnosis and five-year survival rates among patients with breast cancer to patient navigation services [12].

Like the poor, those with low health literacy may benefit from patient navigator programs, inasmuch as they often have less knowledge about their medical conditions and treatment, worse health status, less understanding and use of preventive services and a higher rate of hospitalization than those with marginal or adequate health literacy [13]. In addition, the average annual health care costs of persons with very low literacy (reading at the grade level two or below) may be four times greater than those of the general population [14]. The barriers faced by those with limited health literacy along with the promising results of the earliest patient navigator programs has led to the call for more research on the effectiveness of such programs in overcoming health system barriers and reducing disparities in care.

The National Cancer Institute (NCI) currently sponsors eight institutions through its Patient Navigator Research Program which develops and tests interventions among populations that experience cancer health disparities, i.e., members of racial and ethnic minorities, individuals with lower socioeconomic status and residents of rural areas [10]. NCI also held a Patient Navigator Academy in 2005 which brought together patient navigators from across the country [11]. And HRSA's Bureau of Primary Health Care provides training to community health workers through their Migrant Health Program and their Healthy Communities Access Program, although the latter was unfunded in fiscal year 2006 [15].

### **Patient Navigator Outreach and Chronic Disease Prevention Act of 2005**

The Patient Navigator Outreach and Chronic Disease Prevention Act of 2005 (Patient Navigator Act) was signed into law on June 29, 2005 [16]. Under this legislation, the secretary of Health and Human Services, acting through HRSA, may provide grants to eligible entities for the development and operation of patient navigator services for the purpose of improving health care outcomes [17]. These grants require recipients to recruit, assign, train and employ patient navigators who

have direct knowledge of the communities they serve to facilitate the care of individuals [18].

Duties of patient navigators include: (1) acting as contacts by assisting in the coordination of health care services; (2) facilitating the involvement of community organizations in helping individuals who are at risk for or who have cancer or other chronic diseases; (3) notifying patients of clinical trials and, upon request, aiding in enrollment of eligible individuals; (4) anticipating, identifying and helping patients overcome barriers within the health care system; (5) coordinating with the relevant health insurance ombudsman programs to provide information to individuals who are at risk for or who have cancer or other chronic diseases; and (6) conducting ongoing outreach to health disparity populations [19].

Those eligible for grants under the act include public or nonprofit health centers, health facilities operated pursuant to a contract with the Indian Health Service, hospitals, cancer centers, rural health clinics, academic health centers and nonprofit entities that enter into a partnership to provide patient navigator services [20]. Authorized appropriations for the Patient Navigator Act were: \$2 million for fiscal year 2006, \$5 million for fiscal year 2007, \$8 million for fiscal year 2008, \$6.5 million for fiscal year 2009, and \$3.5 million for fiscal year 2010. Although funding for the first year did not come through, the full \$5 million authorized for fiscal year 2007 was included in the Senate Labor, Health and Human Services Appropriations bill [21]. An evaluation component the Patient Navigator Act requires the secretary to study these demonstration programs, report to Congress on program results and make recommendations to improve patient outcomes in other public health areas [22]. Continued funding of the Patient Navigator Act is key to obtaining the data necessary to determine the effectiveness of and the need for patient navigator programs in the future.

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