

Cancer Patient Navigation: Where Do We Go From Here?

As cancer care screening, treatment protocols, and insurance coverage become increasingly complex, community cancer centers face a dilemma as to how best to guide patients and families through the experience. Increasingly, community cancer centers are turning to patient navigation as one answer to this challenge. In 2003 the National Cancer Institute (NCI) identified over 200 cancer care programs that were providing Patient Navigation.¹ Since then, the American Cancer Society (ACS) alone has initiated another 137 programs. The term “patient navigation” has, however, no centrally agreed upon definition, and navigator programs vary widely. This article provides an overview of the current field of patient navigation, including an overview of three major cancer patient navigation programs. We discuss advantages and challenges faced by patient navigation programs. Finally, we provide a list of eight key questions to help assess whether and what type of patient navigation program would be useful in a given setting.

An Historical Overview

In 1990 Dr. Harold Freeman established the nation’s first patient navigation program at Harlem Hospital Center in New York City. The goal of this program, which was initially funded by an ACS grant, was to assure that “an individual with a suspicious [breast] cancer-related finding will receive timely diagnosis and treatment.”² Additionally, the hospital center provided free and low-cost screening mammography, as well as substantial outreach and public education efforts in its neighborhood. With all three of these interventions in place, the five-year survival rate for patients diagnosed with breast cancer at Harlem Hospital jumped to 70 percent in 2000³ compared to 39 percent in 1986.⁴ This program is still in existence today, and from this pilot program, patient navigation has grown into a national movement and encompasses programs sponsored by organizations such as ACS, NCI, and the Centers for Medicare & Medicaid Services (CMS), as well as “home-grown” programs in hospitals and community cancer centers across the country.

Since the 1990 pilot project, “patient navigation” as both a term and a concept has become increasingly nebulous. C-Change, a large coordinating organization for cancer groups, states: “Patient navigation... refers to individualized assistance offered to patients, families, and caregivers to help overcome health care system barriers and facilitate timely access to quality medical and psychosocial care.”⁵ However, this definition



is put into operation differently within various models of patient navigation in terms of:

- Who provides the assistance (lay people, cancer survivors, nurses, social workers, or other healthcare professionals)
- What types of assistance are provided and the scope of service (transportation, counseling, financial assistance, etc.)
- Who qualifies to receive services (certain diagnoses only or all diagnoses, medically underserved, uninsured, etc.)
- When assistance begins (pre-diagnosis, diagnosis, or at another time)
- When service provision ends (proscribed time period, end of treatment, follow into survivorship).

In practice, this lack of consistent parameters for patient navigation has led to role confusion among members of the healthcare team. It also makes it difficult to establish best practices and outcome measures. In an effort to assist, the Association of Community Cancer Centers (ACCC) updated its *Cancer Program Guidelines* in 2009 to include a section on the rationale and characteristics for patient navigation services. These are intended as guidelines, not as standards.⁶

Patient Navigation Models

Currently, three national models of patient navigation are in use, in addition to a plethora of “homegrown” and hybrid programs. As mentioned above, the three national models are sponsored by ACS, NCI, and CMS. A brief description of each follows.

The ACS Patient Navigation Program. ACS launched its patient navigation program in 2005, with the aim of “providing reliable patient education and information to support informed decision making, resources, and emotional support for those touched by cancer.”⁷ ACS Patient Navigators are full-time ACS staff members, who are placed in cancer treatment facilities across the country. ACS Patient Navigators offer help to people with any type of cancer, work with patients after diagnosis, and continue to support the family and caregivers as they transition to their home communities. Currently, ACS has 137 ACS Patient Navigators in the United States with additional programs in the pipeline.

NCI’s Patient Navigator Research Program (PNRP). NCI also launched its program in 2005 but with the aim “to decrease time between cancer-related abnormal finding, definitive diagnosis, and delivery of quality standard cancer care.” NCI Navigators are lay community members or professionals. (See the March/April 2010 *Oncology Issues* article, “Longitudinal Network Patient Navigation,” for a

description of the PNRP underway in Washington, D.C.). NCI’s PNRP is a research study, so it offers help to breast, cervical, colorectal, and prostate cancer patients enrolled in the study. Currently, NCI has nine major sites and navigation begins after screening abnormality or diagnosis of cancer.

CMS’ Cancer Prevention and Treatment Demonstration for Ethnic and Racial Minorities. CMS launched its program in 2006 with the aim “to help minority beneficiaries navigate the healthcare system in a more timely and informative manner and facilitate cancer screening, diagnosis, and treatment to improve health care access and outcomes, as well as lower total costs to Medicare.”⁷ Similar to the NCI program, CMS navigators can be lay persons or professionals. As a demonstration project, navigation services are offered to Medicare or Medicaid beneficiaries with proven or suspected breast, cervical, colorectal, lung, or prostate cancer. This demonstration project was initially scheduled to last four years. CMS currently has six sites, and the navigation start point can be at screening, diagnosis, or treatment.

Patient Navigator Qualifications, Training, and Certification

When Dr. Freeman started the patient navigation movement at Harlem Hospital Center, the criteria for navigators did not include a specific level of formal education. Navigators were required to be culturally attuned to the community they were serving, knowledgeable about the local healthcare system, and highly connected with critical decision-makers within the system, especially with the financial decision-makers.²

Since that time, some programs have continued to use lay navigators, while others have made formal education a requirement, such as a college degree, a social work degree, or a nursing degree. Post-employment training for navigators varies markedly. Some navigators receive little or no training while others are encouraged or even required to attend educational conferences. For example, *The National Cancer Patient Navigator Education Program*, a three-day continuing education conference for navigators, sponsored by ACS, NCI, and CMS, has occurred annually from 2006 through 2008. In 2008, more than 300 individuals attended the program.

Most recently, certification programs for patient navigators are now being offered—although as yet there are no generally agreed upon criteria for “certification.” The Harold P. Freeman Patient Navigation Institute offers certification, and the National Consortium of Breast Centers (NCBC) offers certifications for nurses and radiation technologists for two types of Breast Patient Navigators. One

of the opportunities for patient navigation as a whole lies in defining core competencies for the different types of navigators.

Successes and Challenges for Patient Navigation Programs

Patient navigation programs with a focus on screening and outreach, such as the one started by Dr. Freeman, have had the most demonstrable success. The initiation of the Harlem Hospital program correlated with a nearly 30 percent increase in five-year survival rates among women diagnosed with breast cancer.² Another patient navigation program in New York City for colorectal cancer patients located at Lincoln Medical and Mental Health Center was able to reduce “no shows” from 67 percent to 10 percent, decrease wait time between initial visit to procedure from ten weeks to two weeks, and increase early detection by as much as 50 percent.⁸

Other patient navigation programs have successfully helped patients address and overcome financial barriers (underinsured and uninsured), communication barriers, and systemic barriers (transportation, missed appointments, follow-up calls).^{2,12} Overall, patient navigation programs are bringing about increases in screening, and adherence to diagnostic follow-up care after the detection of an abnormality.⁹ Many believe patient navigators who act as a bridge between the medical culture and the patient’s culture are the most successful.¹⁰

A major challenge for many patient navigation programs has been professional role confusion. Depending on the job description, patient navigators are sometimes added to the healthcare team to do a job that other members of the healthcare team had already been doing.¹¹ As a function, “patient navigation” is not new to the medical field. Helping patients and families “navigate” the healthcare system has been a part of nearly every oncology healthcare professional’s daily work for decades. With the advent of a position titled “Patient Navigator,” the challenge has become how to define patient navigation as an entity with a job description that is distinctly different from already existing members of the healthcare team.

The challenge of defining “Patient Navigation” is a crucial one to confront, because—without a clear definition—role confusion will continue and research will be hampered. Dohan and Schrag have suggested that a barrier-focused definition of patient navigation may be more advantageous than a service-based one. When a service-focused definition of patient navigation is used, the services tend to overlap with other positions in cancer care, such as social work, nursing, education, and case




management. However, when the focus of a patient navigation program is on assisting patients to overcome barriers to care, less room for role confusion and more room for collaboration exists.¹²

Another challenge for patient navigation programs is achieving “buy-in” from *all* stakeholders on the aim of and need for such a program *prior to* implementation. For patient navigators to be successful, they must be an integrated part of the healthcare team. This integration is much more likely to happen when each member of the healthcare team understands his or her responsibilities and those of other members of the team. After implementation, multidisciplinary meetings (including patient navigators, social work, nursing, outreach, and other team members) that provide education on respective roles and referral processes, as well as serving as arenas for open communication, are also helpful. Interdisciplinary communication is a must in setting up a successful program.

Lastly, patient navigation programs must also find a way to comply with HIPAA regulations. If the navigator is an employee of the institution, complying with HIPAA is usually not a problem. However, some specialized navigation programs employ outside lay persons or professionals to provide services inside the community cancer center or hospital setting. The referral process becomes difficult, because patients must either self-refer, or members of the healthcare team must secure written permission before making a referral.

Food for Thought

Of the three major programs providing patient navigation programs currently, two are research studies (NCI and CMS) and the third is financially supported by ACS. The efficacy and cost-effectiveness of patient navigation programs is still under study.⁹ In June 2005, President Bush signed into law the Patient Navigator, Outreach, and



How these patient navigation programs can be financially sustained is a looming question for many community cancer centers.

Chronic Disease Prevention Act, authorizing federal grants to hire and train patient navigators and \$2.9 million was appropriated in 2007 for this initiative.¹³ The U.S. Department of Health and Human Services (HHS) Health Resources and Services Administration (HRSA) awarded \$2.4 million in 2008 for two-year demonstration projects, but HRSA does not anticipate a new competition for this demonstration program.¹⁴ Patient navigation is also being funded through entities in the private sector, such as foundations and pharmaceutical companies. These types of funding are not a long-term solution, however, and at present patient navigation is not a billable service.

How these patient navigation programs can be financially sustained is a looming question for many community cancer centers.

If your cancer program is contemplating initiating a patient navigation program, here are some preliminary questions to consider:

1. What need is your organization hoping to address with a patient navigation program?
2. What is your organization's measurable goal for the program?
3. What are the target populations you hope to serve?
4. What specific functions, tasks, and services will patient navigation provide and who in your organization already provides these?
5. Who are the stakeholders in the program?
6. How will you fund the program? Is this funding mechanism sustainable?
7. How will you distinguish a patient navigation program from other programs and services?
8. What measures will you use to determine success in your patient navigation program?

Patient navigation in the context of oncology care can and should take different forms as dictated by individual needs. The challenge for the medical community is how to maximize understanding and integration of these different roles and definitions, to ensure the best outcome for all. Coming to a consensus is crucial. Specifically, the healthcare community as a whole should come to consensus in:

- Defining the term patient navigation
- Identifying and developing effective, sustainable program models
- Creating navigator job descriptions
- Agreeing on and then ensuring appropriate educational requirements, curricula for training, credentialing, and certification

- Identifying best practices in patient navigation
- Developing standards of care
- Collecting outcome measures.

These steps are crucial for the U.S. cancer care system. There is a tremendous need to coordinate all of the efforts in patient navigation into a cohesive collective. Integration is paramount as we move forward. ■

Ashley Varner, MSW, MBA, LCSW-C, is a member of the Association of Oncology Social Work and senior director, Caregiving Programs with the Cancer Support Community. Pam Murph, LCSW, is a member of the Association of Oncology Social Work and an oncology social worker in private practice.

References

- ¹Hede K. Agencies look to patient navigators to reduce cancer care disparities. *J Natl Cancer Inst.* 2006; 98:157-59.
- ²Freeman HP. A model patient navigation program. *Oncol Issues.* September/October, 2004;19(5):44-46.
- ³Oluwole SF, Freeman HP, et al. Impact of a cancer screening program on breast cancer stage at diagnosis in a medically underserved urban community. *J Am Coll Surg.* February 2003;196(2):180-188.
- ⁴Freeman HP, Wasfie TJ. Cancer of the breast in poor black women. *Cancer.* June 1989;63(12):2562-2569.
- ⁵C-Change. What is cancer patient navigation? Washington, DC: C-Change 2009. Available online at: <http://www.cancerpatientnavigation.org>. Last accessed March 15, 2010.
- ⁶Association of Community Cancer Centers. *Cancer Program Guidelines.* Rockville, MD: Available online to members at: <http://www.accc-cancer.org>. Last accessed March 15, 2010.
- ⁷American Cancer Society. *2008 Patient Navigator National Training Handbook.* Atlanta: ACS.
- ⁸New York City Health. Colonoscopy patient navigation: A resource kit to help you get started. New York City: New York City Health. Available online at: <http://www.nyc.gov/html/dob/downloads/pdf/cancer/colon-patient-toolkit.pdf>. Last accessed March 15, 2010.
- ⁹Wells K, Battaglia T, Dudley D, Garcia R., et al. Patient navigation: State of the art or is it a science? *Cancer.* 2008;113(8):1999-2010.
- ¹⁰Institute for Alternative Futures. Patient Navigation Program Overview: A report for the Disparity Reducing Advances (DRA) Project. April 13, 2007. Institute for Alternative Futures. Available online at www.altfutures.com/draproject/pdfs/Report_07_02_Patient_Navigator_Program_Overview.pdf. Last accessed April 2, 2010.
- ¹¹Hermann J. Patient navigation: whose job is it? *Oncology Issues,* September/October 2005;20(5):48.
- ¹²Dohan D, Schrag D. Using navigators to improve care of underserved patients. Current practices and approaches. *Cancer.* August 15, 2005;104(4):848-855.
- ¹³Newman-Horm PA. C-Change. Cancer Patient Navigation: Published Information. Washington, DC: C-Change; 2005.
- ¹⁴U.S. Department of Health and Human Services Health Resources and Services Administration. Patient navigator outreach and chronic disease prevention demonstration. Washington, DC: HRSA 2010. Available online at: <http://bbpr.hrsa.gov/patientnavigator>. Last accessed April 2, 2010.