
CASE 1

Establishing a Navigation Program in a Statewide Multifacility System

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The following two case studies reflect the development of oncology nurse navigation and lay navigation, both of which were successfully integrated in a program at the Northside Hospital Cancer Institute (NHCI). NHCI is a community cancer program serving the Atlanta metropolitan area. This program includes three acute care hospitals and two affiliated medical oncology practices spanning 32 offices across 29 counties in northern and central Georgia.

The Oncology Patient Navigation Program was initiated in 2010 with NHCI's participation in the National Cancer Institute Community Cancer Centers Program (NCCCP). This navigation program began with four hospital-based oncology nurse navigators (ONNs). After six years, that number grew to 25, including 15 ONNs and 10 lay navigators. These navigators cover not only the three hospitals within the system, but also 13 offices of the affiliated medical oncology practices. Program management and strategic planning are centralized under the oversight of an oncology patient navigation program coordinator, who ensures consistency and uniformity across the system, allowing for coordinated, systematic growth of the program.

What methods were used to assess the need for and structure of the navigation program?

From the inception of navigation at NHCI, the intent was to build a formalized navigation program with a leadership and supervisory

structure, rather than simply adding navigators and having no dedicated leadership. To ensure the program's success, it was important to understand the navigation processes already present in the organization and evaluate all areas of the oncology continuum.

A gap analysis is the first step in designing and building any navigation program (Mack & Shalkowski, 2014). At NHCI, this assessment was conducted by key personnel and physicians in the oncology continuum to identify areas where navigation potentially could be valuable. Information was thoroughly evaluated in a community needs assessment, which included identified areas of focus by the hospital system as well as data from the cancer registry regarding volumes in specific tumor types.

Mack and Shalkowski (2014) emphasized the importance of a “systematic design, using qualitative and quantitative information to gain insight for program development” (p. 50). To this end, a literature search on navigation was completed, and information was gathered on other navigation programs throughout the country via site visits, phone calls, and emails to key personnel. The information obtained from these steps was used in building the program.

As with any new role in health care, the ONN role at NHCI was surrounded by questions. For example, how was the ONN role different than that of the oncology social worker, the case management staff, or even other oncology nurses in the system?

Although a preliminary job description was written at the onset of the program, it became apparent that additional work was necessary to redraft this description to further characterize this distinctive role.

How was the role of the ONN differentiated from other roles within the NHCI program?

Early in NHCI's literature search on navigation, information was obtained on the implementation of the navigation role in Canada. The country's publicly funded system enabled oncology navigation to become implemented and studied, leading to the development of literature about its programs. Of particular interest to NHCI was a professional navigation framework validated in a Canadian context. Fillion et al. (2012) felt that the literature failed to describe cancer navigation consistently and that confusion over the role was related to the “lack of acknowledgment of the bidimensional nature of the role” (p. E58). This bidimensional role consisted of a health

system-oriented first dimension focusing on the continuity of care of the patient and a patient-centered second dimension focusing on patient empowerment. This framework most closely matched NHCI's goals of moving the patient through the system efficiently and meeting the patient's psychosocial needs.

The Supportive Care Framework for Cancer Care also was used as a foundation in the implementation and delivery of navigation services. Formulated by Fitch in 1994, this framework was "designed as a tool for cancer care professionals and program managers to conceptualize what type of help cancer patients might require and how planning for service delivery might be approached" (Fitch, 2008, p. 6).

When evolved into practice, these frameworks helped to differentiate the ONN role and build the theoretical foundation for the NHCI program.

Finally, core competencies developed by the National Coalition of Oncology Nurse Navigators and the Oncology Nursing Society (ONS) were used to fill specific functions and outline the job description of the ONN role.

These competencies and their development were critical for two reasons. First, they prevented the ONN role from becoming defined by assigned "tasks." Many times, the tasks of the navigator became so numerous and unrelated to the role that the potential positive influence on the patient was lessened (Advisory Board Company, 2011). Second, they ensured that the ONN role had a specific scope of practice moving forward, as the lay navigation component was added.

NHCI wanted to avoid a duplication of services among the navigation team (nurse and lay) and confusion among the healthcare system staff and patients. Although some overlap inevitably would occur, enough delineation was present to ensure that all navigators understood their role.

To further differentiate the two, lay navigation team members were called *cancer care liaisons* (CCLs). In the Oncology Patient Navigation Program, the role of the disease site navigator is reserved for ONNs who have clinical expertise, while the CCLs function as support and provide both system and community resources for patients.

The program's initial launch began with a program coordinator and four ONNs in the sites of breast, lung, gynecology, and gastrointestinal tumors. These sites were decided based on information obtained from the cancer registry related to total patient volume at NHCI.

How were the actual processes of navigation developed for the tumor-specific sites?

Prior to the initiation of the navigation program, a national consulting firm advised in its early development and outlined a process for ONNs to receive referrals for patients from NHCI's oncology registry pathology reporting system; however, during the gap analysis, it was determined that working through this system might actually lead to delays in identifying oncology patients needing navigation. Further surveys were conducted in each of the sites to determine how patients moved through the disease continuum and what providers, clinicians, and others involved in patient care viewed as the best initial entry point of navigation as well as potential points of navigator intervention. From this, processes and written algorithms were developed.

With this framework in place, so began the process of continual evaluation and change based on the needs of patients, caregivers, and the system. The NCCCP Navigation Assessment Tool was used not only to provide a baseline assessment of the navigation program as a whole, but also to establish algorithms within the individual disease site programs. The tool also was used in the development of future goals in each of the disease sites (Swanson, Strusowski, Mack, & Degroot, 2012).

Each program functioned in slightly different ways. The breast ONNs received their referrals from the positive pathology reports of patients who were biopsied at Northside Hospital. The gynecologic ONNs received referrals from mid-level providers assigned to the inpatient unit where patients were sent after surgery (as gynecology patients frequently are not positively diagnosed until the time of surgery). The thoracic ONNs most often received referrals for patients with a strong suspicion of lung cancer who also were undergoing diagnostic procedures. Although ONN functions were slightly different in each disease site, every patient encounter began with a standardized assessment developed for NHCI patients.

Why is navigation assessment important?

ONNs are able to use their knowledge and skill to assess patients and identify potential barriers to care (Gentry & Sellers, 2014).

Assessment is important, as it provides a baseline for the ONN to formulate a plan to support and care for both patients and caregivers. Although no standardized navigation assessment exists, each program develops its own, adapts a model from another program, or uses other types of psychosocial screening.

The NHCI navigation program started with the development of a basic assessment tool based on adaptations from several other programs. After a period of initial use, it became apparent that further revision or the adaptation of another assessment tool was needed. With further research, a navigation assessment was developed based on seven categories found in Fitch's (2008) framework: physical, informational, emotional, psychological, social, spiritual, and practical. These categories have allowed for more in-depth assessment and determination of patient and caregiver needs. Not only is information from this assessment used by the ONN, but it also is conveyed to a multidisciplinary conference coordinator to alert the multidisciplinary care team of any potential issues that may influence patient care and additional needs.

The initial expectation of the NHCI navigation program was that all patients would be navigated. It became increasingly apparent that this probably would not be possible based on a multitude of factors, including patient refusal of navigation, increasing analytic case volumes, patients diagnosed at NHCI but treated elsewhere, and patients who were not identified because of the many points of entry along the cancer continuum. The next section will address how to target patients most in need of navigation services.

How are NHCI patients identified for navigation, and which patients most likely need navigation?

Patients in need of nurse navigation are identified by direct referral from physicians and staff; through multidisciplinary conferences, hospital census reports, surgery schedules, and screening programs; or from self-referral inside or outside the system. Regardless of how patients are identified, the concept of *patient-centered care*, where patients are “listened to, informed, respected, and involved in their care—and their wishes are honored,” is applied first and foremost as an indispensable principle in the navigator program (Epstein & Street, 2011, p. 100).

Although the ONN, physician, or staff may think a patient requires navigation assistance, the patient may not feel that way. Navigation is offered as a service to patients, and patients always retain the right to refuse this service.

Fitch's (2008) framework, used in the development of the navigation program at NHCI, has basic clinical standards for the supportive care of patients with cancer. Two of these standards are significant in determining the process of referring patients to navigation.

The first standard states, "All individuals have the opportunity to be referred to an appropriate supportive care resource" (Fitch, 2008, p. 12). All NHCI patients should be given the opportunity to be referred to navigation. To this end, physicians and staff are educated about the services offered by navigation. A brochure and letter detailing the services of the navigation program are provided to the patients, along with a navigation-specific phone number and email address. In addition, navigation is highlighted on the NHCI website (www.northside.com/Oncology-Patient-Navigation) and through multiple print publications available to the community.

The second standard states, "All individuals have the opportunity for self-referral to supportive care resources" (Fitch, 2008, p. 12). ONNs proactively contact patients identified as needing navigation services. From that initial contact it is left to the patient to continue proactive contact or initiate contact at a later date. Patients who prefer to initiate contact need to be educated on available navigation services at any point along the cancer continuum. Determining the patients most likely to need navigation remains an ongoing discussion; patients who would seem to have the greatest need often do not use the navigation services, and patients with a seemingly low need may contact the navigator on a regular basis.

Currently, no validated acuity systems exist in navigation; however, the Billings Clinic in Montana developed an acuity system to help ensure a more standardized workload for each navigator (Blaseg, 2009). NHCI currently is working on an acuity scale that combines elements of the Billings system with characteristics of patients of higher need at NHCI. The hope is that this scale will allow for a more even distribution level of care and act as a guide to determine which patients require a more proactive, hands-on approach from navigation.

Since November 2010, NHCI has added ONNs in the new tumor type sites of melanoma/sarcoma, neurologic, general, and screening. It also has added additional ONNs in lung and breast.

NHCI also has participated in the Centers for Medicare and Medicaid's Health Care Innovation Challenge Awards grant as a Cancer Care Network affiliate of the University of Alabama at Birmingham, adding lay navigation to the system. This program has added six staff to NHCI's navigation program. After the initial year of the grant, it was recognized that lay navigators (or CCLs) could further delineate their role on the NHCI navigation program team. The greatest need was found to be in the affiliated medical oncology offices. A pilot project was initiated with one CCL in one medical oncology practice. This project has since expanded to an additional five CCLs serving eight affiliated medical oncology practices.

How does the CCL function in medical oncology practices?

Although many functions exist in navigation, not every function requires a trained oncology nurse; thus, the lay navigator role was created. Common questions asked within NHCI include the following:

- What is the current need?
- Who is the best person to meet that need?

For example, a nurse does not necessarily need to be making appointments or coordinating transportation. A CCL with these areas of expertise might enhance the experience between the patient and caregiver.

Medical oncology practices most often are staffed with RNs with expertise in oncology who already provide the clinical teaching, symptom management, and care coordination roles. The CCL job function and description was developed with input from physicians, nurses, and clinic managers, along with the core competencies for non-clinically licensed patient navigators created by the George Washington University Cancer Institute (Pratt-Chapman, Willis, & Masselink, 2014). CCLs are ambassadors for NHCI, helping to link affiliated practices with services and resources provided and also providing an additional helping hand in hallways and infusion areas. CCLs also are patient advocates, identifying resource-based and financial patient needs and linking patients and caregivers with resources best suited to meet their needs. Finally, CCLs empower patients and caregivers by making resources available to them to manage disease and the continuum of care.

What is next for the NHCI Oncology Patient Navigation Program?

Moving forward, NHCI has three objectives for its patient navigation program:

- Expand metric identification and gathering.
- Revise software systems to meet the needs of the growing program and allow for greater intrasystem navigation.
- Continue expanding and integrating ONNs and CCLs throughout the system.

Summary and Key Points

A need exists for both nurse and lay navigators within health-care systems, as both bring tremendous benefit to patients with cancer and their families. In 2005, the National Cancer Institute began studying navigation with the Patient Navigation Research Project. With additional emphasis placed on navigation in NCI's Community Cancer Center Program and the creation of the American College of Surgeons Commission on Cancer patient navigation standard, programs all over the country have started developing their own navigation programs.

Although every navigation program is different, NHCI's program was created with standard steps, providing a blueprint for other programs. Dedicated leadership of the navigation program, along with a systematic design process pulled from a vast array of information and resources, gave the program a strong foundation. This strong foundation and framework (80% of the program), combined with allowance for individualization within the disease site (20%), has contributed to the program's success.

The NHCI program continues to evolve, as it employs continual evaluation, develops assessment tools, and changes based on the needs of patients, caregivers, and the system.

- Careful evaluation of the healthcare system and its current processes—both inpatient and outpatient—is crucial prior to the design of any new navigation program.
- To avoid role confusion and ineffectiveness, it is imperative that ONN core competencies are used and role delineation and scope of practice are determined.

- Careful assessment of how patients with cancer move through a specific healthcare system will allow identification of gaps in care, consequently enabling effective and useful algorithms for navigation.
- Assessment is a cornerstone of nursing practice and the practice of ONNs. Careful, in-depth assessment of the oncology patient allows for a plan to meet patient and caregiver needs and inform other healthcare team members of potential issues.
- Every patient with cancer does not necessarily need or want to be navigated; however, all should be aware of navigation and have access to it.

Questions

What is the importance of core competencies in oncology patient navigation?

Core competencies provide the “fundamental knowledge, skills, and expertise required” for navigators to proficiently perform their role (ONS, 2013, p. 7). These competencies can be used for all levels of ONNs—from novice to experienced—as well as for administrators and institutions developing job descriptions, training tools, and materials; evaluating processes; and addressing personal or professional development for ONNs (ONS, 2013).

Why is patient-centered care as important as evidence-based care?

Evidence-based practice, the use of available research and clinical expertise focusing on the best patient outcomes, seems to be at odds with the idea of *patient-centered care*, where patients are “listened to, informed, respected, and involved in their care; and their wishes are honored” (Epstein & Street, 2011, p. 100). The best outcomes need to be defined by what is “meaningful and valuable to the individual patient” (Epstein & Street, 2011, p. 100).

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