

Patient Navigation: A “Win-Win” for All Involved

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The words “you have cancer” are some of the most devastating words a patient will ever hear. Initially, patients are “often immobilized by fear and uncertainty” (Gentry & Sein, 2007, p. 8). Even as patients and their families are facing one of the greatest challenges of their lives, they will be asked to navigate a complex healthcare system while coordinating the multiple treatment plans they will face. At this time, they need someone to serve as their guide on this frightening journey. Patient navigator programs are streamlining the oncology care continuum, ensuring timely treatment and follow-up, and preventing patients from “falling through the cracks” (Gentry & Sein).

Patient navigation in cancer care refers to individualized assistance offered to patients, families, and caregivers to help overcome health system barriers and facilitate timely access to qualified medical and psychosocial care (Fowler, Steakley, Garcia, Kwok, & Bennett, 2006). Navigation programs for patients with cancer focus on working with patients and their families at various points along the continuum, with some beginning at diagnosis and continuing through all phases of the cancer experience (C-Change, Inc., n.d.; Yates, 2004). Patients and families value the individualized support provided by patient navigators throughout their cancer journeys. Patient navigators can connect patients to resources and support systems, help streamline appointments, help patients access financial services, assist with transportation needs, reduce patients’ and families’ anxiety, identify appropriate social services, and track interventions and outcomes (see Figure 1). Navigators can save valuable time and reduce problem-solving time for patients, ensuring that they are offered appropriate services in a timely manner. Although the initial model of navigation was designed for low-income patients, the model has evolved to assist people from all socioeconomic back-

grounds. Patient navigator programs have become a “value-added service” in cancer care clinics and hospitals all over the country. As the patient navigator model has evolved, it has taken on a variety of forms, usually dictated by the needs of the patients and experience of the institution or setting. Social workers, case managers, lay people, and nurses have filled the role of navigator. Private patient navigator services even exist for those who want to hire a navigator and can afford to pay hourly fees. This article shares the development of a patient navigator program in a small community hospital in the southeastern region of the United States.

The Nurse Navigator Concept

The navigator concept was introduced by Harold P. Freeman, MD, and implemented in 1990 at Harlem Hospital in New York (Freeman, 2006). The program was funded by a grant from the American Cancer Society, and the goal of the program was to reduce or eliminate cancer disparities in the poor and underserved populations that bear a heavier burden of cancer. As a result of the disparities, higher cancer incidence and mortality rates and lower survival rates existed. Freeman identified barriers that affected the timely diagnosis and treatment of cancer, including lack of insurance, poor social support, poor coping styles, and poor health literacy skills. Freeman was the first to identify an association between low socioeconomic status and racial differences in cancer survival. Freeman’s original patient navigator pilot program launched a national movement.

Overview of One Institution’s Navigator Program

Duke Raleigh Cancer Center in North Carolina is a nationally accredited cancer center, and the staff is comprised of a

multidisciplinary team of physicians, nurses, radiation therapists, tumor registrars, dietitians, social workers, spiritual counselors, clinical trial coordinators, genetic counselors, palliative care coordinators, and patient navigators. The center is affiliated with Duke Raleigh Hospital, a 186-bed community hospital which offers excellent care in a community setting. Duke Raleigh Hospital is a member of the Duke University Health System, which is a National Cancer Institute–designated Comprehensive Cancer Center. Duke Raleigh Cancer Center serves a broad community and provides expert care to a varied spectrum of malignancies, ranging from breast, head and neck, gastrointestinal, lung, prostate, endocrine, gynecologic, skin, brain, and the lymphomas.

Duke Raleigh Cancer Center employs two navigators. Although their job descriptions are alike in many ways, the professional background of each navigator is quite different. Each navigator brings individual strengths; together, they have developed an innovative and successful program. Julie McQueen, RHed, CHES, is a two-time breast cancer survivor and a certified health education specialist with a degree in public health. She facilitates a vibrant breast cancer support group that meets monthly and navigates patients with breast cancer from initial screening through diagnosis, treatment, and follow-up. As part of her navigator position, McQueen has become the outreach coordinator for the cancer center by serving on cancer boards on the local and state levels. The boards include the Susan G. Komen Race for the Cure® and the Pretty-in-Pink Foundation. Brenda Wilcox, RN, BSN, OCN®, is a 20-year oncology nurse and is responsible for navigating all other site-specific diseases, including gastrointestinal, lung, colon, head and neck, and the lymphomas. Wilcox also coordinates a thoracic multidisciplinary clinic within the cancer center and helps

- Program planning and implementation
- Supportive care triage
- Coordination of care across the continuum
- Patient and family education
- Management of complex cases
- Psychosocial support
- Consistent patient follow-up
- Initiation of consultations with other disciplines
- Facilitation of timely procedures and appointments
- Monitoring of patient interventions
- Tracking of patient outcomes
- Marketing of patient navigation services
- Program evaluation
- Development of multidisciplinary programs
- Community outreach programs
- Resource management

Figure 1. Key Roles of the Patient Navigator

Note. Based on information from Desimini et al., 2009; Frelick et al., 2006; Gentry & Sein, 2007; Pfizer Oncology, 2005; Rabinowitz, 2004.

facilitate a general cancer support group that also meets monthly at the cancer center. Both women have combined efforts to bring Duke Raleigh Cancer Center's patient navigator program to a unique level of patient care, making the navigator role one of undisputed value to colleagues and the patients and families they serve.

Implementation of the Nurse Navigator Role

At Duke Raleigh Cancer Center, the patient navigator process ideally begins with the referral of a newly diagnosed patient by the diagnosing physician. A patient then is contacted by the navigator and introduced to the benefits of the navigator program. The patient navigator assures the patient and family that the navigator is available to answer questions, address concerns, offer support, meet educational needs, and, essentially, navigate them throughout the often complex course of care and treatment. The navigator provides the patient with contact information and encourages him or her to phone for any reason to get questions or concerns addressed immediately. The navigator then assists the patient in scheduling necessary appointments and reassures the patient that he or she will be greeted

at the first visit to the cancer center. Thus begins the devoted commitment of the patient navigator to lead and guide the patient and empower that person with knowledge and understanding of the disease process, treatment options, symptom management, and support resources. Each new patient is given a one-on-one "New Patient Orientation" developed and taught by the assigned navigator. This includes the principles of chemotherapy and/or radiation therapy, in addition to any teaching regarding symptom management that might be necessary. Each patient is given an educational packet of information to reinforce the teaching and to provide materials that are pertinent to the care and treatment that will be administered for the specific disease. A "Patient Navigator Brochure" and business card contain contact information for the patient and family.

The Navigator Role Across the Cancer Continuum

A patient typically meets with the nurse navigator at the initial appointment with the medical oncologist and then is contacted by phone for follow-up to clarify any areas of confusion and ask any questions after meeting with the physician. A patient is seen by the navigator at each chemotherapy appointment and at least once weekly during the course of radiation therapy. A navigator who is in close contact with patients during treatment can be a valuable asset by quickly and effectively triaging patients for management of treatment-induced side effects. Monitoring adherence and response, as well as ensuring correct usage of prescribed antiemetics and analgesic management, are important parts of routine assessment by the navigator. Patients receiving concurrent therapies are monitored more closely with the help of ongoing assessment by the navigator.

Documentation of patient assessment and navigator interventions begins at initial contact with the patient. Documentation and communication with the primary oncologist are other important roles of the nurse navigator. Documentation includes: (a) the date of interaction as well as the interaction itself, (b) details of specific education and teaching materials used, (c) referrals to other interdisciplinary team members (e.g., social worker, spiritual counselor, psychologist, clinical trials coordinator, end-of-life care), (d) any faxed information shared with patient and family members, (e) copies of

phone triage interactions, and (f) copies of physician orders and follow-up.

Navigators serve to augment care wherever necessary within the cancer center. As patients suddenly find themselves thrown into a whirlwind of what seems like an endless sea of information and medical terminology, a navigator becomes a consistent "go-to" resource to assist patients in making sense of what they are being told by the medical team, thereby reducing the risk of crisis (Hoelz, Sladek, & Michaelson, 2007). Navigators also serve to identify and communicate valuable information on behalf of patients to the nurses and physicians who provide their care, thus enhancing quality of care.

Case Example

Scheduling time to listen to patients discuss whatever is concerning them enables nurse navigators to proactively address issues before they become problematic. A patient, N.B., phones the navigator and expresses concern that the physician has said his metastatic colon cancer cannot be cured. The patient continues to express that because his cancer is incurable, he has no reason to undergo the treatment that has been recommended to him by his physician, especially because it is negatively affecting his quality of life. Transportation to and from his appointments is difficult because he shares a car with his working wife. N.B. also complains of difficulty eating and states that the only foods that appeal to him at the present time are cold beverages and ice cream, which cause him discomfort when he eats. The navigator, during the course of conversation with the patient, identifies that the patient does not understand that, although the disease is not curable because of its metastatic nature, his disease is potentially very treatable and can be controlled. The navigator is in a position to help the patient re-evaluate the goals of treatment. He can be assisted in seeing the changed goal to stop or slow disease progression, promoting the maintenance of a good quality of life. The navigator foresees that the patient may indeed have survivorship issues dealing with life with an incurable disease and suggests individual or group counseling.

In checking the physician's prescribed chemotherapy regimen, the navigator realizes that the patient's treatment plan includes the use of oxaliplatin, a drug that causes discomfort when patients become exposed to cold temperatures. With

this information in mind, the navigator reinforces to the patient that cold foods and beverages are to be avoided for a few days after treatment with oxaliplatin and addresses the need for a consultation with a dietician to assist the patient in identifying foods that he can eat and enjoy during treatment. Finally, a social worker in the cancer center is consulted to arrange transportation assistance to and from treatment while the patient's car is unavailable. The navigator communicates her assessment and interventions to the physician on behalf of the patient and alerts the nurses who will be administering the chemotherapy that the patient is in need of additional reinforcement regarding chemotherapy side effects and symptom management. At the end of the navigator's interventions, N.B. understands that although his disease is not curable, he has hope; although he cannot have cold foods and beverages after treatment, that is temporary and a dietician will provide suggestions; and lastly, transportation issues have been resolved.

On occasion, when patients are admitted to the hospital for aggressive symptom management, such as neutropenic sepsis, the navigator continues to offer supportive care by being a liaison to the nurses and physicians, by making frequent visits to patients during hospitalization, and by communicating with the primary physician. Patients and families are reassured that the nurse navigator is their advocate across the cancer continuum of treatment and follow-up.

Multidisciplinary clinic coordination is another important role of the nurse navigator. At Duke Raleigh Cancer Center, the nurse navigator coordinates the multidisciplinary clinics and provides continuity of care for patients newly diagnosed with a thoracic malignancy. Figure 2 outlines the steps of patients referred to multidisciplinary clinics and the important role of the nurse navigator in providing continuity of care and patient education.

An example of continuity of care provided by a nurse navigator is a newly diagnosed patient with lung cancer. The navigator is responsible for coordinating the initial appointment and explaining to the patient and family the process of the multidisciplinary clinic (Seek & Hogle, 2007). The navigator explains to the patient that he or she will be seen by a team of specialists—a thoracic surgeon, medical oncologist, and radiation oncologist—on the same day, at the same appointment, and in the same

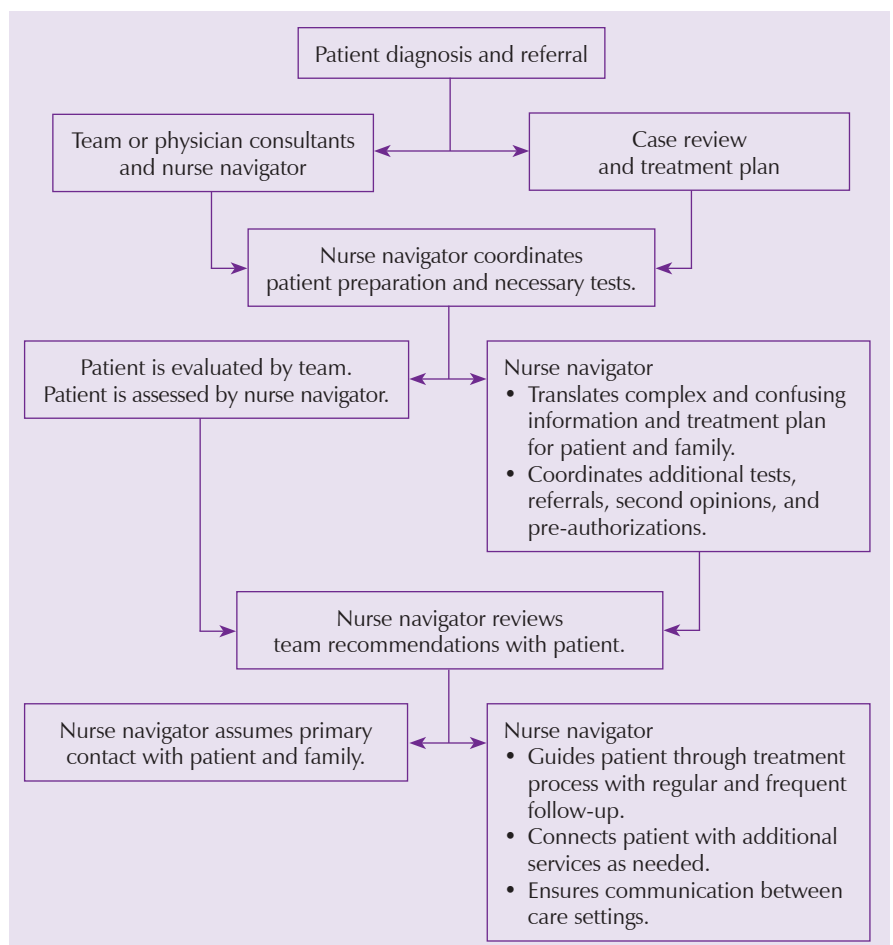


Figure 2. Role of Nurse Navigator in Multidisciplinary Clinics

Note. Based on information from Desimini et al., 2009; Frelick et al., 2006.

clinic setting. The navigator educates the patient about any staging studies necessary prior to multidisciplinary clinic. In the example, tests may include pulmonary function studies, positron-emission tomography, computed tomography, and magnetic resonance imaging of the brain. At the multidisciplinary clinic, the patient is seen by all physicians involved in the treatment plan, and the nurse navigator educates the patient and family regarding treatment goals, provides an educational packet of appropriate information, and then explains the process that the patient can expect when he or she presents the first time for treatment at the center. The navigator discusses the treatment schedule for the patient and communicates to the nursing staff the information and education that have been provided to the patient and family. The navigator also offers specific information that is important to support the patient's health-belief system or lifestyle, such as having chemotherapy treatments at the end of the

week to allow weekend recovery and return to work on Monday.

Navigators Making a Difference: Ensuring Continuity of Care

The nurse navigator role can be incredibly fulfilling, bringing satisfaction to nurses when they engage in the lives of the patients served and cared for. In the role of nurse navigator, the nurse enters into a relationship with a patient at diagnosis and augments every area of care throughout the entire course of the cancer journey, whether ending in survivorship or end-of-life care. Patients and loved ones quickly become close to the navigator, realizing that he or she will always remain a constant resource and advocate on their behalf and be easily accessible and always attentive to their needs. As the navigator provides patients with knowledge and understanding, anxieties that center around fear of the unknown begin to decrease, and patients

begin to feel more at ease, more empowered to focus energy on getting well and taking back some of the control that was robbed by their diagnoses. Initially, at diagnosis, patients and families feel overwhelmed—in a state of shock and disbelief. The role of the nurse navigator is a professional assigned to guide them through decision making, problem solving, and psychosocial needs. The test of time proves the navigator to be trustworthy in attending to patient and family needs, initiating follow-up, returning phone calls in a prompt fashion, relaying messages to physicians on patients' behalf, and obtaining answers to patient and family concerns—providing continuity of care and follow-up.

The experienced oncology nurse is perfectly positioned for the navigator role across the specialties of oncology. Although various descriptions of navigators are emerging nationwide, the experienced oncology nurse possesses a comprehensive knowledge base of the pathophysiology of cancer, treatment modalities, disease progression, and symptom management. An experienced oncology nurse is able to problem-solve and proactively support and initiate patient referrals based on the anticipated needs of the patient during the planned course of treatment. Certainly one of the most important roles of the oncology nurse is the ability to explain information that is being discussed or handed to the patient by other healthcare providers, and to help the patient and family or significant other to understand the treatment plan and other aspects of care. Based on a patient's educational level, translating medical information on an ongoing basis is a vital function of the nurse navigator role, as the diagnosis alone causes shock and denial coupled by an inability to process a lot of information at one time. National oncology certification as set forth by the Oncology Nursing Certification Corporation ensures that oncology nurses possess extensive understanding of malignant processes, psychosocial and emotional ramifications of illness on patients and caregivers, patient educational needs throughout the course of care, and symptom management with current cancer therapies. An understanding of the healthcare system in its entirety enables oncology nurses to smoothly transition patients from one area to the next as well as quickly be able to obtain needed consultations with other disciplines that the nurse identifies as necessary in providing holistic care.

Nurse Navigator Program Development and Evaluation

Many different types of nurse navigator programs exist, along with various preparations and expectations (Institute for Alternative Futures, 2007). The decision to be disease-specific or general, as well as degree of educational preparation, occurs at the program's inception. Very little consensus exists as to actual roles and responsibilities of nurse navigators. For Duke Raleigh Community Cancer Center, the navigator must have an in-depth understanding of how the cancer center functions and what role each member of the cancer care team plays. Patient care processes must be examined to identify gaps in care and areas where navigation can achieve more seamless and enhanced patient care. Physicians, nurses, social workers, and all members of the team must be made to understand that the navigator role is meant to enhance, augment, and help streamline patient care, not to overlap or infringe on care that is being delivered by other members of the team. Physicians should be educated that the information a navigator provides serves only to reinforce what the patient has already been told by the physician and to assist patients by providing resources to enhance their understanding. The navigator's role assists not only patients and families, but also physicians, nurses, and other care providers within the cancer center. Enhanced communication among healthcare providers builds relationships within the team and directly enhances patient care as all work together to meet individual patient and family needs. Building a navigator program involves administrative support, interdisciplinary teamwork, and evaluation criteria that identify cost-effectiveness and evidence-based standards for the intended program (see Figure 3).

Evaluation of the navigator program is integral to the program to ensure that the desired outcomes of the patient population being served and the organization are being achieved. Program evaluation provides objective information that can help others have a clear understanding of how the program works and the benefits it provides to patients. Data that are collected and reviewed for other purposes (tumor registries, quality improvement, and patient satisfaction) can be used to validate the effectiveness of the program (Frelick, Strusowski, Petrelli, & Grusenmeyer, 2006; Hoelz et al., 2007). Common program outcome measures include re-

1. Identify key stakeholders, patient groups in need, and current available resources.
2. Define the scope of the nurse navigator's involvement, job description, necessary educational preparation, and expectations.
3. Identify and understand the process already in place.
4. Identify weaknesses, gaps in care, and dissatisfiers to patients and families, as well as points along the continuum when patients can fall out of the system with the current processes.
5. Identify potential barriers and obstacles.
6. Determine program scope, cost, and implementation strategy.
7. Collect baseline data and perform a needs assessment.
8. Develop a plan to address weaknesses in the current process.
9. Develop a plan to go "above and beyond" in customer service.
10. Implement support systems, referral processes, and outreach strategies.
11. Develop program outcome measures based on identified gaps, problems, and national quality-of-care standards and expectations.
12. Evaluate the program.

Figure 3. Key Steps to Building a Navigator Program

Note. Based on information from Desimini et al., 2009; Pfizer Oncology, 2005; Seek & Hogle, 2007.

duced wait times and times to treatment; volume changes of patients who have accessed the program on an annual basis and stayed in the system when compared with prior years without nurse navigator involvement; satisfaction surveys that document patient and family feedback regarding navigator services provided; and quality improvement, cost-effectiveness, decreased denied insurance, and decreased hospitalizations because of treatment complications (Desimini et al., 2009; Frelick et al.; Gentry & Sein, 2007; Seek & Hogle, 2007).

Conclusions

Patient navigation has become an important component of cancer care. Patient navigator programs are improving timely access to diagnosis and treatment, assisting patients and families in managing and coordinating cancer care, decreasing complications from treatment by managing symptoms promptly, and increasing patient quality of life. The

specialty of oncology is a prime example of utilization of the nurse navigator role. Patients with cancer receive numerous treatment modalities (e.g., surgery, chemotherapy, radiation), often need guidance and intervention to support symptom management from disease and treatment, and, lastly, require specialized psychosocial care to address the fear and apprehension that accompany life-threatening illness. The nurse navigator provides the patient and family, from diagnosis through survivorship, an advocate who offers support, education, guidance, and reassurance. The major goal of the newly developed role of nurse navigator is to advocate for the patient and family by coordinating and augmenting care among all interdisciplinary team members. Nurse navigators strive to provide optimal cancer care in a complex and, for the patient and family, overwhelming journey that requires numerous treatment modalities and follow-up services.

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References

C-Change, Inc. (n.d.). Cancer patient navigation overview. Retrieved from <http://www.cancerpatientnavigation.org>
Desimini, E.M., Rice, T.T., Williams, D.R.,

Marmorstein, P., Farrell, P.W., Faunce, H., . . . Lewis, M.G. (2009). Establishing a breast care network in a nine-facility healthcare system. *Oncology Issues, March/April*, 36–45. Retrieved from https://accc-cancer.org/oncology_issues/articles/marapr09/desimini.pdf

Fowler, T., Steakley, C., Garcia, A.R., Kwok, J., & Bennett, L.M. (2006). Reducing disparities in the burden of cancer: The role of patient navigators. *PLOS Medicine*, 3, 974–976. doi: 10.1371/journal.pmed.0030193

Freeman, H. (2006). Patient navigation: A community based strategy to reduce cancer disparities. *Journal of Urban Health*, 83, 139–141. doi: 10.1007/s11524-006-9030-0

Frelick, R.W., Strusowski, P., Petrelli, N., & Grusenmeyer, P. (2006). Oncology nurse care coordinators as navigators. Improving cancer disease management and the patient experience. Retrieved from http://www.accc-cancer.org/oncology_issues/articles/julaug06/navigators.pdf

Gentry, S., & Sein, E. (2007). Taking the wheel. Oncology nurses help patients navigate the cancer journey. *ONS Connect*, 22(3), 8–11.

Hoelz, T.M., Sladek, M.L., & Michaelson,

P.L. (2007). Blending nursing roles in oncology and imaging: An innovative strategy. *Oncology Nursing Forum*, 34, 27–31. doi: 10.1188/07.ONF.27-31

Institute for Alternative Futures. (2007). The DRA Project: Accelerating disparity/reducing advances. Patient navigator program overview. Retrieved from http://www.altfutures.com/draproject/pdfs/Report_07_02_Patient_Navigator_Program_Overview.pdf

Pfizer Oncology. (2005). *Establishing a patient navigation program—An implementation guide for the program champion from patient navigation in cancer care: Guiding patients to quality outcomes*. New York, NY: Author.

Rabinowitz, B. (2004, November). Improving patient care through interdisciplinary breast cancer management. *Business Briefing: Women's Healthcare*, 1–4.

Seek, A., & Hogle, W.P. (2007). Modeling a better way: Navigating the healthcare system for patients with lung cancer. *Clinical Journal of Oncology Nursing*, 11, 81–85. doi: 10.1188/07.CJON.81-85

Yates, P. (2004). Cancer care coordinators: Realising the potential for improving the patient journey. *Cancer Forum*, 28, 128–132. Retrieved from <http://eprints.qut.edu.au/1739/1/1739.pdf>

Leadership & Professional Development

This feature provides a platform for oncology nurses to illustrate the many ways that leadership may be realized and professional practice may transform cancer care. Possible submissions include, but are not limited to, overviews of projects, accounts of the application of leadership principles or theories to practice, and interviews with nurse leaders. Descriptions of activities, projects, or action plans that are ongoing or completed are welcome.

Manuscripts should clearly link the content to the impact on cancer care. Manuscripts should be six to eight double-spaced pages, exclusive of references and tables, and accompanied by a cover letter requesting consideration for this feature. For more information, contact Associate Editor Mary Ellen Smith Glasgow, PhD, RN, CS, at maryellen.smith.glasgow@drexel.edu or Associate Editor Judith K. Payne, PhD, RN, AOCN®, at payne031@mc.duke.edu.