Oncology

A snapshot of their educational background, compensation, and day-to-day roles and responsibilities

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Nurse Navigators

The life-changing event of a cancer diagnosis causes fear, anxiety, and confusion for patients and families. In addition to questions and concerns about the disease and its impact on their quality of life, today patients and families also face far more complex treatment and follow-up decisions than they have in the past. Treatment may involve surgery, followed by several rounds of chemotherapy and radiation, which can last hours at a single session. Patient care teams may also include up to a dozen specialists. Hospital and health systems nationwide are increasingly turning to oncology nurse navigators to provide needed support and guidance to help patients and families traverse the complexities of the cancer care delivery system.

A New Standard in Cancer Care

Across the country, patient navigation has rapidly become an essential component of cancer care. Since its early days in the 1990s with Harold Freeman's model (see box on page 42), patient navigation has demonstrated great promise with reducing or eliminating many of the common barriers associated with cancer care. Recent studies have also found that cancer patients assigned to a patient navigator were about 20 to 30 percent more likely than control subjects to comply with diagnostic follow-up care after an abnormality was detected.¹

This finding and similar evidence-based research has led oncology-related accrediting organizations to integrate patient navigation as a required standard for program accreditation, including the National Accreditation Program for Breast Centers, which instituted a patient navigation standard in 2009. Most recently, the Commission on Cancer (CoC) of the American College of Surgeons added standard 3.1 that emphasizes the need and importance of navigation services. This standard, initiated in 2012, requires the phase-in and documentation of navigation services by 2015. To meet the standard, the CoC requires cancer programs to:

- 1. Conduct a community health needs assessment at least once every three years to address healthcare disparities and barriers to care for patients (see pages 32–34 for more)
- 2. Establish a patient navigation process and identify resources to address barriers that are provided either on site or by referral to community-based or national organizations
- 3. Annually assess barriers to care and the navigation process to evaluate, document, and report findings to the cancer committee
- 4. Modify or enhance annually the patient navigation process to address additional barriers identified by the community health needs assessment.

Oncology Nurse Navigators

Institutions are increasingly using oncology nurse navigators to assist with the management of cancer patient access, diagnosis, and treatment because of the navigators' deep understanding of our healthcare system and experience communicating with a range of healthcare professionals within our communities.

A focus on coordinating and improving patient care and outcomes is consistent across all navigation programs; however, the dynamics of each institution and patient population shape the specific roles and responsibilities of oncology nurse navigators within each program. Some key factors that could influence the development of a navigation program include:

- Patient dynamics (e.g., the number of patients, race, incidence and case mix, ethnicity, and income distribution)
- The medical staff model of the cancer center (e.g., employed, private practice, and/or mixed)
- Administration and physician support for the navigation program
- Commitment to tumor-specific, supportive care, and/or disparities programs
- Personality, credentials, and "flexibility" of the oncology nurse navigator
- Size, scope, and geographic proximity of all program elements—the total program.

The Role of the Oncology Nurse Navigator

Working on a multidisciplinary cancer care team, oncology nurse navigators serve in many roles-both within and beyond the scope of their clinical responsibilities-to benefit the patient. According to the National Coalition of Oncology Nurse Navigators (NCONN), navigators often serve as clinical facilitators, care providers, educators, counselors, and patient advocates. For example, in a recent NCONN survey, one breast care navigator described her duties at a busy breast center as "ensuring timely follow-up and care coordination for patients with diagnostic mammograms with BIRADS (Breast Imaging Reporting and Data System) 4 classifications, or possible malignancies." In addition to educating patients on the biopsy procedures (ultrasound and stereotactic) and assisting with both scheduling and performing the actual biopsy, this nurse navigator also provides critical follow-up with the patient and referring physician in the six months following the procedure.

Oncology nurse navigators provide an ongoing, consistent point of contact for patients and families as they transition between different care delivery settings along the care continuum, including diagnostic services, inpatient and outpatient settings, specialty consultations, research, hospice, and/or palliative care. They help expedite the time to diagnosis, ensure fewer delays in treatment, facilitate communications between the various care providers, and answer questions and clarify complicated clinical information for patients and families. As patient advocates, oncology nurse navigators help connect patients and families to other medical or community resources they may need during or following their course of treatment, such as nutrition, transportation, financial assistance, and/or support groups.

The National Coalition of Oncology Nurse Navigators

NCONN defines the oncology nurse navigator as a professional whose clinical nursing expertise guides patients, families, and caregivers to informed decision-making; col-

Table 1. Common Patient Barriers

FINANCIAL BARRIERS

Unable to afford health insurance

Medicare or Medicaid ineligibility

Losing employment that provides healthcare insurance

Lack of affordable cancer services

LOGISTICAL BARRIERS

Lack of transportation

Living at a far geographic distance from healthcare

Lack of reminder system(s)

Lack of understandable cancer information

SOCIO-CULTURAL BARRIERS

Limited social support

Inadequate health literacy

Source: American Cancer Society. *Report to the Nation: Cancer in the Poor.*

laborating with a multidisciplinary team to allow for timely cancer screening, diagnosis, treatment, and increased supportive care across the cancer continuum. When NCONN first formed in 2008, the majority of oncology nurse navigators were employed by hospital systems; however, this trend is slowly changing. More and more medical and radiation oncology practices are adding navigation as a service offering. According to data that individuals must provide on the NCONN membership application, oncology nurse navigators are most often found in the community hospital setting, with about 60 percent employed by a hospital or health system, and the remaining working for oncology clinics or medical oncology practices. The oncology nurse navigator's role in patient education is vast, encompassing:

- Disease-specific navigation
- Treatment options
- Processes
- Clarification on physician-provided information
- Directives
- Information on what patients can expect overall on the cancer journey.

In 2009 NCONN published the first competencies that defined the role of the oncology nurse navigator (see page 41). NCONN developed these competencies through consultation with active practicing professional oncology nurse navigators in a wide variety of healthcare settings throughout the United States. The core competencies cover five areas of proficiency, including:

- 1. Professional, Legal, and Ethical Nursing Practice
- 2. Health Promotion and Health Education
- 3. Management and Leadership
- 4. Negotiating the Healthcare Delivery System and Advocacy
- 5. Personal Effectiveness and Professional Development.

What the Data Tells Us

According to NCONN membership data, oncology nurse navigators are concentrated most heavily in the Midwest,

Figure 1. NCONN Members by U.S. Region



Figure 2. Educational Background of Oncology Nurse Navigators



Mid-Atlantic, and Western regions, representing more than 60 percent of all navigators nationally (see Figure 1, page 38). While there is no specific professional experience, degree, or certification required for nurses to be classified as "oncology navigators," NCONN's current membership data indicates the majority of the organization's 1,000 plus members (73 percent) earned bachelor's and master's degree-level training (Figure 2, page 38). When surveyed about annual compensation a majority of NCONN members (almost 80 percent) report earning a salary in the \$60,000 to 90,000+ range, which is consistent with national salary ranges for bachelor's and master's prepared nursing staff (Figure 3, right). Obviously, these salary ranges can vary widely based on geographic region, caseload management expectations, and the navigator organizational model.

To gain a better understanding of the roles and responsibilities of oncology nurse navigators, the authors of this article—in partnership with NCONN—conducted a random survey of about 725 oncology nurse navigators who are subscribed to the NCONN Listserv. The survey tool "A Day in the Life of a Patient Navigator" can be found on page 43. All survey responses were voluntary and represent a snapshot of the educational background, compensation, and day-to-day roles and responsibilities of oncology nurse navigators. Their tasks and responsibilities varied widely, depending on:

- The specific needs of their patients and organizations
- Disease type
- Patient flow through the system
- Emotional, financial, and physical needs of the patient
- Physician interaction, level of support, and requests for services.

In brief, here are a few key findings from the survey.

As shown in Figure 4 (right), more than half of all oncology nurse navigators are practitioners with professional experience ranging between 21 and 31 years. These oncology navigators consistently reported six main duties:

- 1. Providing patient education
- 2. Explaining diagnosis and treatment
- 3. Coordinating care across multidisciplinary teams and providers
- 4. Assisting with financial issues
- 5. Providing psychosocial support
- 6. Initiating and completing treatment summary plans.

When asked to quantify the amount of time spent on each of their core responsibilities, respondents reported that they spend the majority of their time on the following tasks:

- New patient intake, patient education, appointment scheduling, accompanying patients to visits, etc.
- Patient phone and in-person follow-up
- Transportation issues
- Financial issues
- Social work and counseling.

When asked the number of patients navigated on average

Table 2. Metrics Tracked & Measured by Nurse Navigators

Patient satisfaction and feedback
Physician satisfaction and feedback
Timeliness to diagnosis and treatment
Improved patient outcomes
Preventable ER visits
Referrals to clinical trials
Patient outmigration and retention
Revenue generated for navigated vs. non-navigated patients
Adherence to NAPBC Guidelines
Number and type of patient contacts
Number of new patients seen
Number of referrals to other services
Number of barriers to care
Patient education preferences
Community contacts, including speaking engagements and healthcare fairs

Figure 3. Oncology Nurse Navigator Salary Ranges



Figure 4. Career Experience of Oncology Nurse Navigators



IN THEIR OWN WORDS

No two oncology nurse navigator programs are alike. Further, programs are highly variable dependent on administration and physician support, as well as the flexibility, personality, and commitment of the individual navigator. Here's what oncology nurse navigators have to say about their profession:

Oncology nurse navigators don't have all the answers, but they know how to find the information to guide patients to informed decision-making."

> —Kathleen Gambin, RN, BSN, OCN Northside Hospital Atlanta, Ga.

• Oncology patient navigation is different multi-tasking, every day with every patient...your day consistently evolves, dependent upon the type of patient and his or her individual needs."

> —Helen Roorda, RN, BSN, OCN Florida Hospital Cancer Institute Orlando, Fla.

Truly the responsibilities of a navigator are endless. It is a role of great diversity and flexibility—to really say that I have a set schedule would not portray this work very well. My days vary every day, and I really never know what each day holds and what each person or professional may need from me. I remain on the go with a cell phone in hand to be available for the next person in need."

-Anonymous

"

per FTE oncology nurse navigator, answers varied by type of disease and by program size and scope. On average, most responded that they navigate 150 to 350 total patients (new and ongoing) annually. (This number seemed to back up similar findings on ACCC's online community, MyNetwork, *www. mynetwork.accc-cancer.org.* In a September 2012 exchange, members indicated they navigated an average number of between 120 to 350 new and ongoing patients annually.)

Challenges to Establishing & Expanding Navigation Services

In "A Day in the Life of an Oncology Nurse Navigator" survey, respondents reported facing similar challenges establishing and expanding navigation services. The majority of survey respondents noted the greatest area of challenge is improving physician buy-in and utilization of navigation services. Many described obtaining and sustaining long-term physician support and enthusiasm for the navigation program as hurdles. One respondent shared that physician support tended to wane the longer the navigation program operated.

Another survey respondent commented that, "[her program's] physician champions had really not stepped up to promote the program." As a result, the oncology nurse navigator had to spend a significant amount of time promoting the navigation program—both internally and externally, which was very discouraging to her as a "one-person operation."

Respondents listed resistance from internal staff as an additional barrier. Some reported that internal or external breast and cancer program staff members may believe navigators replace or overlap existing roles—rather than complement them by filling in gaps in services and facilitating the delivery of care. Another survey respondent said that education and open dialogue between cancer care staff and navigators could help to ensure better cooperation among all members of the team and establish more clearly-defined roles and boundaries.

In summary, the most consistently reported challenges to expanding oncology nurse navigator services included:

- A process for obtaining physician buy-in and ongoing support
- A process to ensure that physicians fully utilize services
- Time management
- An effective method for documenting and tracking patients
- A lack of secretarial and resource support
- A process for documenting time and justifying the navigator role to hospital executives.

Measuring & Reporting Program Return on Investment

While oncology nurse navigators receive anecdotal information from patients on the value of their services, quantifying the impact of navigation can often be challenging, particularly given that navigation is not a reimbursed service. Only half of the respondents to the "A Day in the Life of an Oncology Nurse Navigator" survey have some formalized process for tracking and measuring the impact of their services. For

CORE COMPETENCIES FOR THE ONCOLOGY NURSE NAVIGATOR

By enforcing competencies, healthcare professionals establish expectations for performance excellence, resulting in a systematic approach to professional development, improved job satisfaction, and better learner performance. The role of the oncology nurse navigator is evolving as the healthcare delivery system continues to undergo major changes. Technology and access to the Internet have opened new avenues for patients and family members to educate themselves and gain resource information. While this increased capacity to access resources has improved care and reduced delays in treatment, it has also resulted in an overwhelming amount of information to interpret and manage. Navigators continuously emerge from the field of oncology nursing in response to the growing need for patient navigation within the healthcare system for all types of cancer patients.

One major responsibility of an oncology nurse navigator is the coordination of care across the cancer continuum. By accompanying patients through every aspect of their cancer journey, the oncology nurse navigator is best positioned to advocate for and provide guidance to patients and their families. The oncology nurse navigator ensures access to the information necessary for the patient to make the best possible decisions about treatment. The navigator provides counsel and advice to improve the patient's quality of life—and ultimately improve patient satisfaction. Furthermore, the oncology nurse navigator helps decrease healthcare costs through appropriate utilization of healthcare resources.

Apart from the role of a licensed nurse, the oncology nurse navigator needs to develop competencies to integrate the roles of healthcare promoter, educator, counselor, care coordinator, case manager, researcher, and patient advocate. Hence, education programs that prepare oncology nurse navigators must ensure that professional nurses are equipped with the essential competencies that enable them to fulfill these roles capably and ethically. Consistent with national trends, NCONN is developing a healthcare oncology nurse navigator model that provides education and support for the professional nurse navigator. NCONN's core competencies provide a philosophy for oncology nurse navigation and a framework to integrate the oncology nurse navigator's myriad of roles—one of the first items addressed when NCONN formed. The core competencies developed serve the following purposes:

- To frame the philosophy of oncology nurse navigation based on accepted nursing practice
- To define the professional role of oncology nurse navigation and the competencies required to successfully fulfill the role
- To lead the development of curriculum and navigation models that prepare oncology nurse navigators who guide and support cancer patients in a safe and ethical manner
- To inform healthcare employers and the public of what they may expect from an oncology nurse navigator upon entry to practice
- To educate currently practicing oncology nurse navigators to further develop and/or establish a successful navigation program regardless of size, type, or geographical location.

NCONN acknowledges that its core competencies are just a starting point; simply creating the core competencies is not enough. The fluidity of the competencies means NCONN

must always be prepared to adapt them, recognizing that as the healthcare delivery systems change, these competencies must update and evolve to meet the current healthcare delivery standards.

To receive a copy of the Oncology Nurse Navigator Core Competencies, contact the National Coalition of Oncology Nurse Navigators by visiting: www.nconn.org.



most respondents, it is a manual process, typically using Excel worksheets, that begins with the establishment of clearly defined goals and a measure of baseline performance on key metrics or concerns the cancer program aims to address.

When queried about metrics that oncology nurse navigators track and measure, respondents offered a range of answers, including patient and physician satisfaction scores, improved patient outcomes, and patient outmigration and retention (Table 2, page 39). Outcome measurement results will ultimately satisfy program leadership who ask the question: "What is the return on the investment on hiring an oncology nurse navigator?"

Still, few published studies exist on the cost-effectiveness of patient navigation or its benefits to patients. Without outcomes measurement, oncology nurse navigators are not able to show what they know empirically—that positive outcomes are related to navigators and navigation programs. Barriers known to exist and prohibit effective outcome measurements today include:²

• Staff resistance

- · Lack of appropriate software for data collection
- Decreased time and resources required to collect, analyze, interpret, and report the data
- Lack of knowledge
- Varied storage and reporting mechanisms across the organization.

As patient navigation continues to grow, the need for defined standards and common metrics will be essential to compare results across projects and demonstrate both the efficacy and cost-effectiveness of such programs.

The Future of Oncology Nurse Navigation

Current demonstration programs indicate interest at the federal level for exploring patient navigation, but long-term sustainability of these programs, particularly in an increasingly constrained budget environment, is uncertain. However, some in the healthcare field point to the new CoC requirement for patient navigation services as a step toward ensuring the long-term sustainability of these programs. By 2015 all cancer programs will be required to demonstrate the processes and measureable outcomes of patient navigation. In addition, the Affordable Care Act (ACA), which shares many of the same objectives of patient navigation, may also present new opportunities to apply patient navigation to help improve the quality and efficiency of care delivered. One fact is certain, navigation programs, while not widespread statistically, can have a significant impact on the care and well-being of cancer patients with an insatiable need for information and companionship throughout their individual cancer journey.

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THE HISTORY OF PATIENT NAVIGATION

In 1989 the American Cancer Society (ACS) released a report entitled, *Report to the Nation: Cancer in the Poor*, which indicated that poor individuals faced significant barriers that prevented them from obtaining needed oncology care (see Table 1, page 38).

In response to these report findings, oncologist Harold P. Freeman, MD, partnered with ACS to create the first patient navigation program in Harlem, N.Y., in 1990. Targeting women with historically poor breast cancer outcomes, the program helped low-income women overcome barriers to breast cancer screening and follow-up care. Dr. Freeman paired women with suspicious clinical findings with a "navigator" who could help guide them through the maze of the healthcare system. Navigators coordinated appointments with work schedules and stressed the importance of consistent treatment and follow-up. Freeman's model was the first instance that lay navigators, or specially-trained, nonmedical professionals, were used in cancer management. The pilot successfully improved follow-up, reduced wait times for breast biopsies for positive mammograms, and increased early diagnosis of breast cancer.

Given the success of this pilot, in 2001 the President's Cancer Panel recommended that funding be provided to promote community-based programs, such as patient navigator programs, to assist individuals with obtaining cancer information, screening, treatment, and supportive services.

Funding provided by private foundations, including ACS, the Avon Foundation for Women, and Susan G. Komen for the Cure, as well as federal, state, and local governments has led to the implementation and study of more patient navigation programs. In addition, the emergence of several oncology-specific professional organizations, such as the National Coalition of Oncology Nurse Navigators (NCONN) and the Academy of Oncology Nurse Navigators (AONN) also helped fuel the widespread adoption of this growing discipline in cancer care.

Today, the focus of navigation has expanded beyond Freeman's original model to include the timely movement of an individual across the entire cancer care continuum. Now navigators work with patients of all cancer diagnoses and treatment plans, and in a variety of care settings including hospitals, health systems, freestanding cancer centers, and oncology practices.

In fact, the recent ACS *Cancer Treatment and Survivorship Facts & Figures 2012–2013* report stated that "in 2011, 90,000 people relied on the [ACS] Patient Navigator Program to help them through their diagnosis and treatment." ACS collaborates with a variety of organizations, including the National Cancer Institute's Center to Reduce Cancer Health Disparities, the Center for Medicare & Medicaid Services (CMS), numerous cancer centers, and others to implement and evaluate the ACS navigation program.