

# Second Annual NCONN Conference

## *Changing the Face of Cancer Care*

Branson, Missouri, is known as the “Live Music Show Capital of the World,” but for 1 weekend in October, it became the center of the oncology nurse navigator (ONN) universe. On October 8 and 9, navigators from across the country attended the Second Annual National Coalition of Oncology Nurse Navigators (NCONN) Conference at the Branson Convention Center. Entitled, “Changing the Face of Cancer Care,” the event aimed to equip navigators to both justify their role in the healthcare system and enhance their ability to meet patients’ needs. NCONN 2010 provided a hub for navigators to create connections, mentor each other, and receive expert advice on key navigator issues. The Meniscus Educational Institute sponsored the activity for continuing nursing education hours. With features and in-depth interviews, *OncNurse’s* all-NCONN issue provides full conference coverage. For additional NCONN news and resources, check out their new Website at [www.nconn.org](http://www.nconn.org).

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## ON THE SCENE

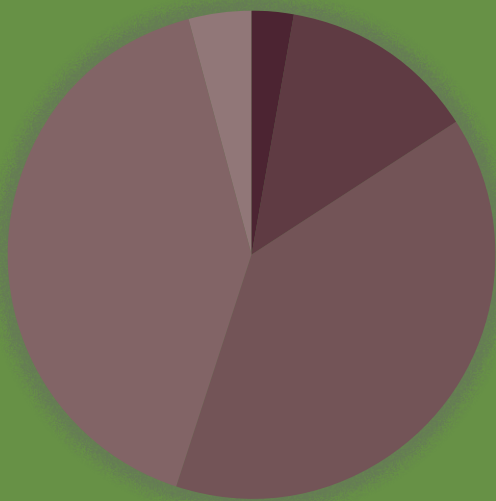
*Images From the Second Annual NCONN Conference*  
**Changing the Face of Cancer Care**



# NCONN MEMBER DEMOGRAPHICS

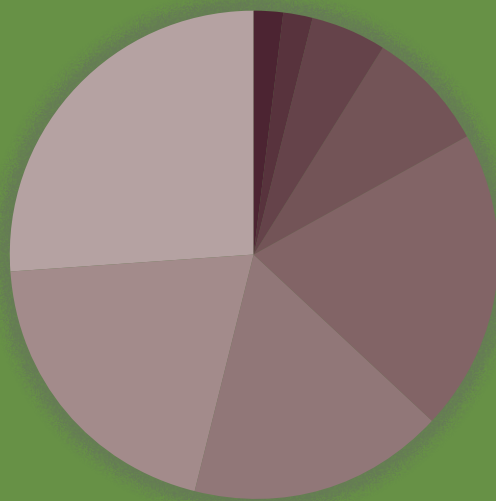
A by the numbers look at the organization that is  
Changing the Face of Cancer Care

NCONN Members by Education



- 3% Diploma
- 13% Associate's
- 39% Bachelor's
- 41% Master's
- 4% Doctorate

NCONN Members by Salary



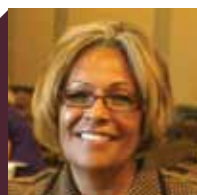
- 2% \$20,000-\$29,999
- 2% \$30,000-\$39,999
- 5% \$40,000-\$49,999
- 8% \$50,000-\$59,999
- 20% \$60,000-\$69,999
- 17% \$70,000-\$79,999
- 20% \$80,000-\$89,999
- 26% \$90,000+

NCONN Members by Career Experience



- 8% 0-5 years
- 10% 6-10 years
- 14% 11-15 years
- 11% 16-20 years
- 15% 21-25 years
- 20% 26-30 years
- 22% 31+ years



Barbara Prisco,  
RN, OCN®Joy Hepkins,  
RN, OCN®Patty Ramey,  
RN, OCN®Shirley Harvey,  
RN, BSN, OCN®Susan Keen,  
RN, OCN®

“When the [navigator] job came up, I applied for it and I said, ‘That’s my job. I want to take care of these patients to make sure they don’t get lost.’”

*When navigators gathered at the Second Annual NCONN Conference in Branson, Missouri, OncNurse was on the scene to take the pulse of the navigator community. Several nurse navigators spoke with us about their experiences in the field, including Patty Ramey, RN, OCN®, Joe Arrington Cancer Center, Lubbock, Texas, Susan Keen, RN, OCN®, Thomas Johns Cancer Hospital, Richmond, Virginia, Joy Hepkins, RN, OCN®, Mercy Fitzgerald Hospital, Darby, Pennsylvania, Shirley Harvey, RN, BSN, OCN®, Texas Health Arlington Memorial Hospital, and Barbara Prisco, RN, OCN®, the Cancer Institute at Florida Hospital Fish Memorial, Orange City.*

### Why did you decide to become an ONN?

**Patty:** Actually, it was a new program that they started at the Joe Arrington Cancer Center. For us it just started about 3 years ago. I’ve always been interested in educating people, and getting to know them, and working with the clients or the patients.

**Susan:** I’ve been an oncology nurse for 10 years. I’ve seen patients come along who got lost in the system. I would try to make everything happen [for them] as quickly as possible because they had lost months—that wouldn’t have happened if there had been somebody there to guide them in the [right] direction, educate them, and follow through. And so I just wanted to be able to be there to help patients, make sure they got the right care they needed. When the job came up, I applied for it and I said, ‘That’s my job. I want to take care of these patients to make sure they don’t get lost.’ And luckily, I was hired to start the program.

**Joy:** Well, I was an oncology nurse for almost 20 years, and this job came about 3 years ago in my institution when they hired a new administrator.

### Can you describe your process for tracking and documentation?

**Shirley:** Right now I’m tracking my information on an Excel spreadsheet that I just made up. That’s where I get my patient information, where I track my phone calls. I track what I’ve done for them and things like that, and it’s very informal. I know that I need to be doing something different. So this conference has given me some ideas in how to develop some tools and see what’s out there from a standpoint of commercial databases. So I’ll have to take this information back to my committee and see what they want to use. They’re going to want to go with something that’s good but something that’s not too expensive.

### Did you have to take any courses or receive new training to become a navigator?

**Patty:** Actually, for us, it was just something new that we’ve been learning. We’ve just read material and then just try to attend whatever [conferences and educational sessions] we can. Then, of course, both my [navigator] colleague and I are oncology certified, so we’ve worked on that.

**Susan:** I had experience and I was already an oncology-certified nurse. Right now I do general navigation, but I’m soon going to be more specialized as a thoracic nurse navigator. There really isn’t a certification program for general navigation, per se. You hear about breast [cancer] because [navigators have] been working with that longer. So we keep looking. We keep hoping that a [thoracic] certification [program] will come up.

**Joy:** No, no, no. I didn’t go to any [classes]. Nobody told us ‘this is how you do it, this is where you go, this is how the job works.’ There was none of that. I just kind of make phone calls. Because that’s the type of person I am, I’m a nurse by calling, so I will do anything for my patient. So, if I don’t know it, I’ll find the access. I’ll find the resources and give them to [my patients].

### Is your hospital supportive of your navigation program?

**Patty:** Very supportive.

**Susan:** Actually, the way my position started, our CEO was on a plane ride. He saw an article [about nurse navigation] in a magazine he was reading. I think it was the airplane magazine, matter of fact, and he came back and told our oncology administrator that he wanted that in their hospital now.

**Joy:** Yeah, they really are. As a matter of fact, last year, I got an award.

**How receptive have patients been to your program?**

**Patty:** Very receptive. We do all one-on-one personalized teaching...when they're newly diagnosed—we meet all new patients when they come in. So they love it because it makes [them] feel special. Everything is personalized for that particular patient when they come into the center.

**Shirley:** They love it—it's really been good for the patients. I also found out some of the patients don't need navigating because they already have their resources in place. The Internet is just awesome. So they already know so much. When they come to me, it's just for validation. So there are some who need everything, some who don't need anything, and then some in between, I'm finding out.

**What are the greatest challenges you have faced in patient navigation?**

**Patty:** I guess right now [we're] spreading ourselves too thin, whereas, when [our program] first started off, you could have more attention for the patient or you could spend more time with them. The busier you get, you have less and less time with [each] patient.

**Susan:** Time. Also, doctors sometimes do not understand that you're there to be an asset to them and also an asset to the patient. You're not trying to take the patient away, but you're trying to make their life and the patient's life easier.

**Barbara:** The biggest challenge I had was the transportation—getting the patients to the [facilities] because they could not get there on their own.

**Do you work with multiple types of cancers?**

**Patty:** We do. We have 6 physicians, and we have 2 nurse navigators and 1 covers 3 physicians and I cover the other 3 physicians. We are not disease specific. We actually cover all tumors or blood disorders, also. Anybody new who walks into our center, we're notified and we'll meet with those patients.

**Do you feel overwhelmed or stressed as an ONN?**

**Patty:** At times. It can be really busy. They're utilizing us more. With [so] many physicians between just 2 nurse navigators, we might be in the treatment room and they're paging us or calling us to [help elsewhere]. And, at present, we haven't even incor-

porated the radiation department. So we're looking into hiring another nurse navigator to start helping us.

**Have you started any patient support groups or do you facilitate different support groups?**

**Susan:** I do. I help facilitate a general support group for lung cancer. Smoking is a big issue, so I also do a group for those who have quit smoking.

**Shirley:** I started a breast cancer support group. We meet once a month, and we have snacks, and we talk about issues, and then we have a speaker. We also have a Look Good...Feel Better program that's done through the American Cancer Society, which teaches women how to apply their makeup, and their scarves, and their hats, and how to style their hair while they're going through treatment...next year, [we're going to start] an I Can Cope program, which is also affiliated with the American Cancer Society.

**Joy:** I built my own support group. It's at the hospital and it's not disease specific because it's a small institution. I [also] work very closely with the American Cancer Society.

**How do conferences like NCONN help you?**

**Joy:** Networking—just meeting other [navigators]. For instance, I didn't know that the documentation and tracking of patients was an issue nationally. I thought it was just [a problem for] me.

**Barbara:** You hear so many different ways of doing things.

**Susan:** You get to network with other navigators. Sometimes when you're having some simple issue in your hospital or facility that you work at, whether it be community-based or whatever, you just can't seem to figure it out, but then you start talking to people, and they're like, 'oh, I had that problem, and this is the way I solved it.'

**Shirley:** It's the networking. It's finding out that other people are in the same situation as you. You're not alone in knowing that you don't know what to do or how to get started. It's finding out what works, what doesn't work. It's just being around people who all have the same focus that I find rewarding...Knowledge is power...[and] the more you know, the more you'll be able to do.

GET  
NCONNected!



If you find the navigators' discussion in this section informative, you may want to join NCONN. One of NCONN's core functions is providing oncology nurse navigators with a platform to network and mentor each other. To this end, NCONN offers a listserv that creates an ongoing exchange of ideas among its members. The organization also provides a discussion board on its Website ([www.nconn.org](http://www.nconn.org)) that includes ongoing forums covering all the major topics in oncology nurse navigation.

VISIT  
[www.NCONN.org](http://www.NCONN.org)

# MODERATED ROUNDTABLE DISCUSSIONS

*Mentoring and Connecting at NCONN 2010*

**Demonstrating its commitment to mentoring and connecting oncology nurse navigators, NCONN kicked off its Second Annual Conference with a series of moderated roundtable discussions. Attendees rotated among three 20-minute sessions covering Core Competencies, Quality Measures, and Tracking and Documentation. The free-flowing discussions allowed navigators to share ideas and solutions with their peers, and participants were eligible for continuing education hours.**

*By Jason M. Broderick*



Kathleen Gamblin, RN, BSN, OCN®, moderates the roundtable discussion on Core Competencies.

## Core Competencies

Core Competencies are essential to defining and sustaining a niche for oncology nurse navigators (ONNs) within the healthcare field. These professional criteria define the ONN specialty using evidence-based standards, set expectations for both healthcare administrators and patients, and establish uniform practice guidelines that can be systematically taught throughout the healthcare community. More than just simple “know-how lists,” navigator core competencies encompass a multifaceted range of technical, clinical, interpersonal, judgment, and problem-solving skills. As NCONN states, the competencies represent the “core set of skills, knowledge, and expertise that the licensed nurse should bring to the ONN position.”

Roundtable participants at NCONN 2010 recognized the importance of core competencies for ONNs. They described having difficulty establishing a clear job description, which resulted in having to perform tasks outside their navigator role. The participants also noted tremendous uncertainty and inconsistency in patient and administrator expectations for navigators. It was agreed that establishing core competencies for navigators would alleviate these issues.

In 2009, NCONN developed the first published set of general core competencies defining the role of the ONN. NCONN collaborated with professional navigators from across the country, including ONNs from both academic settings and community hospitals in rural areas. NCONN’s core competencies provide a philosophy of oncology nurse navigation and a framework to integrate the ONN’s myriad roles as licensed nurse, healthcare promoter, educator, counselor, care coordinator, case manager, researcher, and patient advocate.

The NCONN publication emphasizes 5 specific ONN competence areas: Professional, Legal, and Ethical Nursing Practice; Health Promotion and Health Education; Management and Leadership; Negotiating the Healthcare Delivery System and Advocacy; and Personal Effectiveness and Professional Development. Individual sections of the publication include numbered lists with explanations and implementation strategies for each of the competence areas. NCONN members can access the complete text of the ONN core competencies at [www.nconn.org](http://www.nconn.org).

NCONN acknowledges that their core competencies are just a starting point. At the conference, roundtable moderator Kathleen Gamblin, RN, BSN, OCN®, thoracic oncology nurse navigator, WellStar Health Systems, Marietta, Georgia, stressed that simply creating the core competencies is not enough. She noted that the guidelines are fluid and that NCONN must always be prepared to adapt them. “We recognize... that as the healthcare delivery system starts to change, these competencies are going to need to change,” said Gamblin.





Anne-Marie Williams, RN, BSN, CBCN, leads the Quality Measures roundtable.

# “If we don’t measure what we do, how will we ever really know if we’re successful?”

—Anne-Marie Williams, RN, BSN, CBCN

## Quality Measures

Establishing quality measures for ONNs is imperative to sustaining the growth of the profession. As discussion moderator Anne-Marie Williams, RN, BSN, CBCN, breast oncology nurse navigator, Washington Hospital Center, Washington Cancer Institute, noted at the NCONN 2010 roundtable discussion on quality measures, “If we don’t measure what we do, how will we ever really know if we’re successful?” Moreover, how will navigators demonstrate their value to administrators who decide whether or not to start or keep navigation programs?

The literature provides no specific quality metrics for oncology nurse navigation. Williams said available resources could be adapted to create standardized measures and recommended using the PDCA (plan-do-check-act) model to facilitate the process. She suggested The National Quality Forum ([www.qualityforum.org](http://www.qualityforum.org)) and the Association of Community Cancer Centers (ACCC; [www.accc-cancer.org](http://www.accc-cancer.org)) as two useful starting points.

NCONN attendees received a copy of the ACCC publication *Cancer Care Patient Navigation: A Practical Guide for Community Cancer Centers*. The publication includes navigation outcome measure tools used by Broward Health’s ([www.browardhealth.org](http://www.browardhealth.org)) breast cancer navigation program. The resources include a patient satisfaction survey and lists of specific outcome measures for patient encounters, programmatic components, and performance improvement. Broward also describes outcome measures they adapted from the American Cancer Society (ACS) and how their performance stacked up against the ACS benchmarks.

At the conference, roundtable participants could easily identify and define core success measures, such as patient satisfaction, patient encounters, and programmatic components/performance improvement. However, the difficulties with quality measures arise when deciding how to track the metrics and who should do the tracking—nurses, administrators, or both?

Williams noted administrators often disagree with navigators over what to measure and that it is crucial for navigators to obtain physician buy-in when establishing quality measures. Other key challenges to implementing quality measures include time and resource limitations, as well as difficulty obtaining valid data from all phases of the treatment process.

## Tracking and Documentation

The cardinal rule for tracking and documentation in healthcare is, “If you didn’t track it, you didn’t do it.” At NCONN 2010, ONNs discussed how a lack of documentation negatively affects patient care and exposes ONNs to professional and legal liabilities. According to roundtable moderator Rebecca Trupp, RN, OCN®, CBPN-IC, breast and gynecologic oncology nurse navigator, Suburban Hospital, Bethesda, Maryland, documentation is necessary for ONNs to “show that we take good care of the patient and that we have worth.”

Current literature on nursing documentation stresses the importance of documentation to quality care, noting such areas as coordination of care and evaluation of treatment efficacy. On the legal side, state nursing practice acts maintain that documentation should be clear, concise, and provide an accurate depiction of a patient’s status; however, the documentation laws give healthcare providers considerable latitude concerning implementation of documentation mechanisms. ONNs must ensure that the documentation system used to track their work both supports their professional role and pro-

fects them from liability.

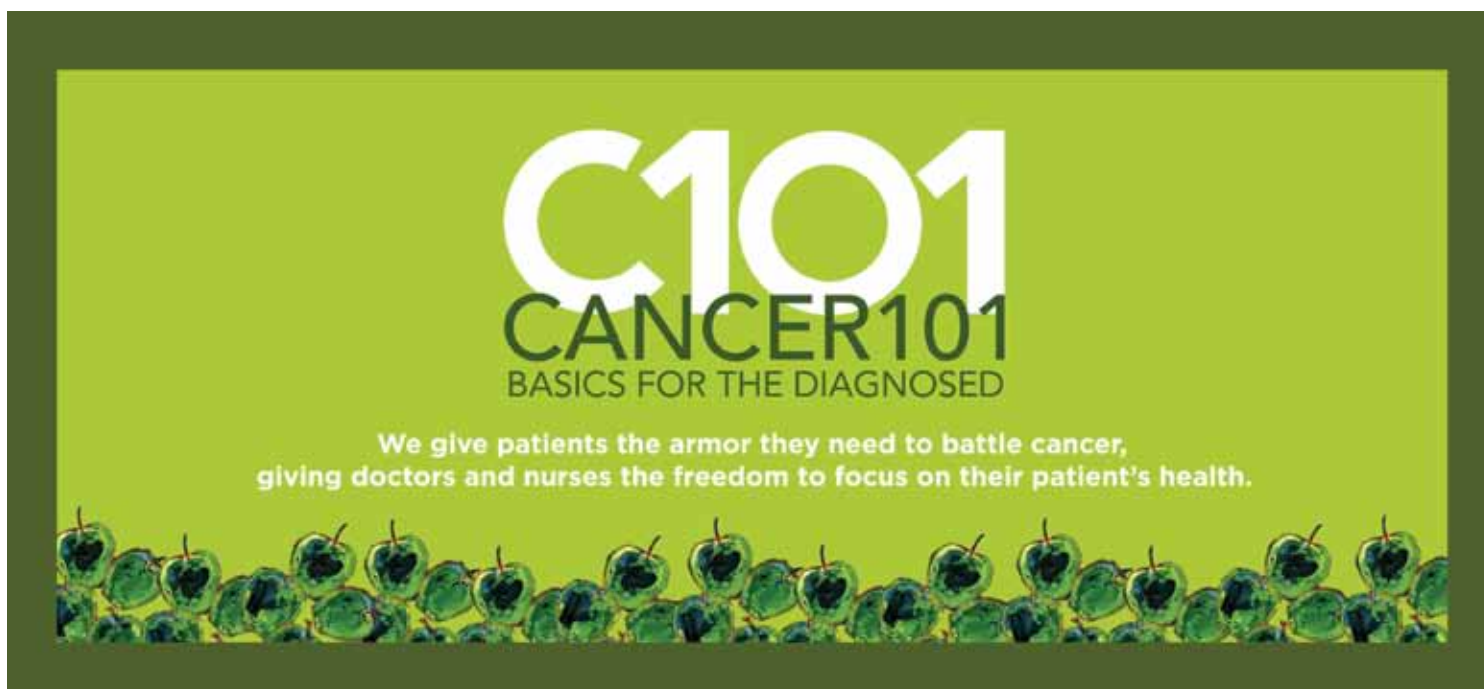
When starting or evaluating a tracking program, Trupp suggested first reviewing currently available resources. Institutions may have EMR or Outlook and Excel programs, and additional tools can be accessed through organizations such as the ACCC. Navigators should also inquire about purchasing new tracking software. Available software programs include NurseNav, Priority Consult, and Open Software Solutions.

Once ONNs are able to create a database with new or existing resources, they need to decide what to track. Some categories suggested at NCONN 2010 included demographics, cancer site, type of referral received, number and type of patient encounters, referral source, and patient satisfaction. Analytics such as collecting outmigration and downstream revenue data are particularly useful in demonstrating the ONN’s positive impact on the bottom line.

The final step involves evaluating the established tracking and documentation system and assessing its efficacy and efficiency. It is imperative that the chosen system meets both the needs of the navigation program and the healthcare facility as a whole.



Rebecca Trupp, RN, OCN®, CBPN-IC (standing, left), moderates the Tracking and Documentation roundtable.



## Tools to Help Patients Navigate Their Treatment Path

By Eileen Koutnik-Fotopoulos

**M**onica Knoll is no stranger to cancer. Her sister is a breast cancer survivor and her father died from esophageal cancer. Still, she was not prepared for a breast cancer diagnosis in 2000.

“When I was diagnosed, I was at a loss for what to do. Once I heard the words ‘you have cancer,’ I felt like I was kicked in the stomach,” she told attendees at the Second Annual NCONN Conference. “I called my nurse ‘Sarge’ because she pushed me around and really told me what to do, which I needed because I was very much in denial.”

Now 10 years later, Knoll is a 4-time cancer survivor with a mission. “Before my cancer, I think I was lost. I didn’t really have a passion for a career. I didn’t really have a big motivating factor in my life,” she said. “Once I started talking with other breast cancer patients, I found we were overwhelmed by the process. There are so many resources we didn’t know where to begin.”

“Navigation was not even a word that was used when I was diagnosed. So many nurses didn’t have the tools they needed to provide for patients. Great resources existed, but there wasn’t a great way to disseminate them,” she said.

### An Idea Is Born

Knoll wanted a way for cancer patients to get these necessary resources. “One of the components with cancer is getting organized. I felt that was missing in the cancer world because when I was diagnosed, there was no way of getting resources organized.”

Taking her experiences and those of other patients with breast cancer and survivors, Knoll founded the nonprofit organization CANCER101—an information resource for cancer patients—in 2002. According to CANCER101’s Website, its mission is “to empower cancer patients and their caregivers to take control over their diagnoses from the moment they learn they have cancer, a recurrence, or metastases through 10 years of follow-up care. Having a plan of attack, the means to stay organized, and access to appropriate resources and information is half the battle to getting through a cancer diagnosis.”

CANCER101 has the following objectives:

- Empower patients and caregivers to get organized and informed to fight their cancer

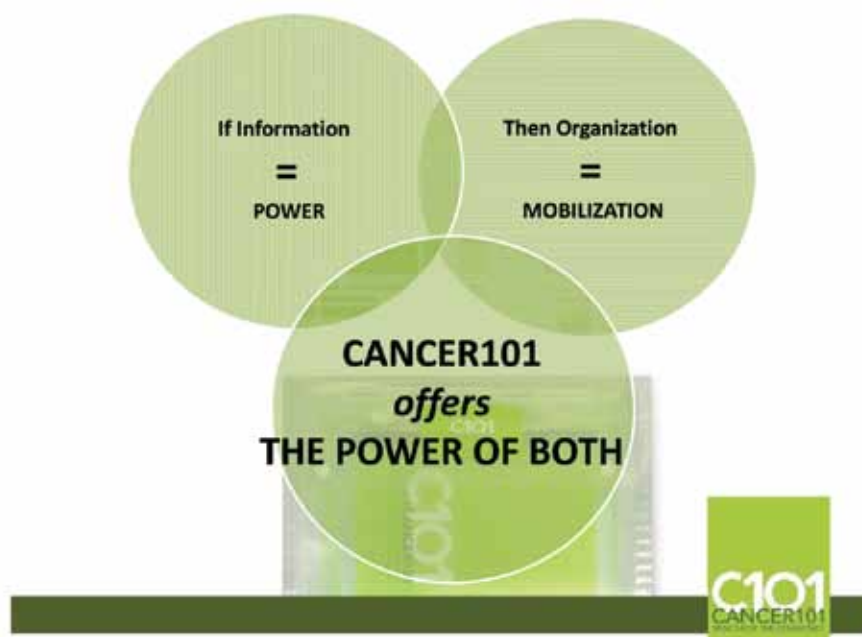
- Help healthcare professionals better manage their patients’ needs
- Educate patients about clinical trials and how to find them
- Ensure patients receive CANCER101’s resources when they need them most: when they learn they have cancer
- Provide complementary wellness support to help patients manage their side effects and emotional well-being
- Provide a unique social media and video campaign that offers nonmedical advice for patients, caregivers, medical professionals, and survivors
- Encourage survivors to educate family and friends about early detection and prevention

### CANCER101’s Program Strategy

Knoll, who serves as the organization’s executive director, explained that the program has a three-fold strategy.



**“Having a plan of attack, the means to stay organized, and access to appropriate resources and information is half the battle to getting through a cancer diagnosis.”**



### ***CANCER101 Planners***

The organization provides free CANCER101 Planners to participating National Cancer Institute (NCI) and Association of Community Cancer Centers across the country. Following the first appointment with an oncology specialist, patients receive Planners that include national resources, important questions to ask their healthcare team, a glossary of medical terminology, a section for tracking medical bills, insurance information, and more. The Planners also include information provided by NCI, the American Society of Clinical Oncology, and the Coalition of Cancer Cooperative Groups (CCCCG). CANCER101 also partnered with NCI to develop cancer-specific information for patients with each tumor type.

The Planner is designed as a tool to help nurse navigators manage their patients' medical needs. "If the nurse navigator organizes the patient, the patient will be more likely to partner and take ownership of their health. If the patient takes ownership, they will allow the nurse navigator to help more patients," explained Knoll.

She recommended that nurse navigators put the Planners together in advance and include additional cancer information and an NCI booklet inside the folder. Nurse navigators also should ensure patients know how to use the Planner, encourage patients

to use the Planner and take it with them to all appointments, and check periodically that patients are filling out the Planner correctly.

### ***The Website***

The Website ([www.cancer101.org](http://www.cancer101.org)) complements the Planner. It offers a live calendar of national teleconferences, Webinars, annual conferences, and retreats. Many of the same resources found in the CANCER101 Planner are available on the Website. An online version of the Planner and a smartphone application are under development.

In addition to CANCER101 resources, the Website provides external links to numerous cancer resources. When you click "National Cancer Resources" under "Get Informed" on the home page, you reach a CANCER101-compiled list of available Web resources covering a variety of cancer topics. Some of the specific topics include advocacy, drug information, employment issues, fertility, and financial help.

Another valuable tool the site provides is the "Learn From Our Partners" section, which hosts cancer resources furnished by CANCER101's strategic partners. The Profiler Tool provided by Nexcura helps patients make informed treatment decisions by giving them access to the latest clinical research relevant to their diagnosis. The CCCC "What Is a Clinical Trial" section offers a Q&A of pertinent clinical trial topics to help patients who are weighing participation in the



Monica Knoll, founder and executive director, CANCER101 (left), With Sharon Francz, LPN, BHA, co-founder and president, NCONN

research programs. The "Questions to Ask Your Doctor" page by Cancer.net facilitates open communication between patients and doctors, which will empower patients as they make crucial treatment decisions.

### ***Social Media***

CANCER101 has launched a social media campaign that offers patients, caregivers, survivors, and healthcare professionals nonmedical advice to help make their lives easier using Facebook and Twitter.

In concluding her presentation, Knoll stressed that CANCER101 and healthcare professionals are a team. "We look at you [nurses] as our customers. We provide these resources to you as well as the patients and want your feedback."

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*Eileen Koutnik-Fotopoulos is a freelance writer based in Keyport, NJ.*

## Returning to the Roots of Patient Navigation

*At the Second Annual NCONN Conference, Steven Patierno, PhD, executive director, George Washington University Cancer Institute (GWCI), challenged navigators to refocus their efforts on the roots of patient navigation: helping individuals, particularly those in poor and underserved communities, overcome barriers to accessing care. He discussed his message in the context of preliminary results and emerging concepts from the 9-site National Cancer Institute (NCI) Patient Navigator Research Program (PNRP), an ongoing initiative examining the efficacy of navigation in cancer care. Patierno is the principal investigator (PI) for the Washington, DC, PNRP site (DC-PNRP), which evaluated the efficacy of navigation services used to address breast cancer disparities. By Jason M. Broderick*



Steven Patierno, PhD, executive director, George Washington University Cancer Institute

### PNRP

PNRP began in 2005 and consists of a series of 5-year grants totaling \$25 million. The program is examining unequal access to standard cancer care and the navigator's ability to alleviate access barriers and reduce delays in delivery of quality diagnosis and treatment. Although the research will benefit all patients, PNRP primarily accrued medically underserved patients, including racial/ethnic minorities, patients with lower socioeconomic status, and rural populations. The study design examined the effectiveness of patient navigation intervention versus standard care alone in patients with either breast, cervical, prostate, or colorectal cancer—4 cancers with tremendous disparities in diagnosis and follow-up.

PNRP officially concluded its 5 years of data collection on September 30. DC-PNRP collected its intervention data via an unprecedented city-wide consortium that united competing medical centers. Data collection required enrolled patients to complete more than 10 survey instruments.

The intervention data for the 9 PNRP projects be-

came available to the PIs on November 15; however, the information is embargoed from public access until Spring 2011. According to Patierno, the embargo is due to the potentially significant societal implications of the navigation data, such as its impact on the Centers for Medicare and Medicaid Services, the Health Resources and Services Administration, and reimbursement overall. With no available intervention results, Patierno instead spoke to NCONN attendees about DC-PNRP's control data and how it reinforces the significance of nurse navigation.

### DC-PNRP A Cancer Disaster Area

Patierno described Washington, DC, as, unfortunately, an ideal location for PNRP analysis. He said the city is a "cancer disaster area," with cancer care disparities that mirror many conditions that Harold Freeman, MD, founder of patient navigation, witnessed when starting his navigation programs in Harlem, New York.

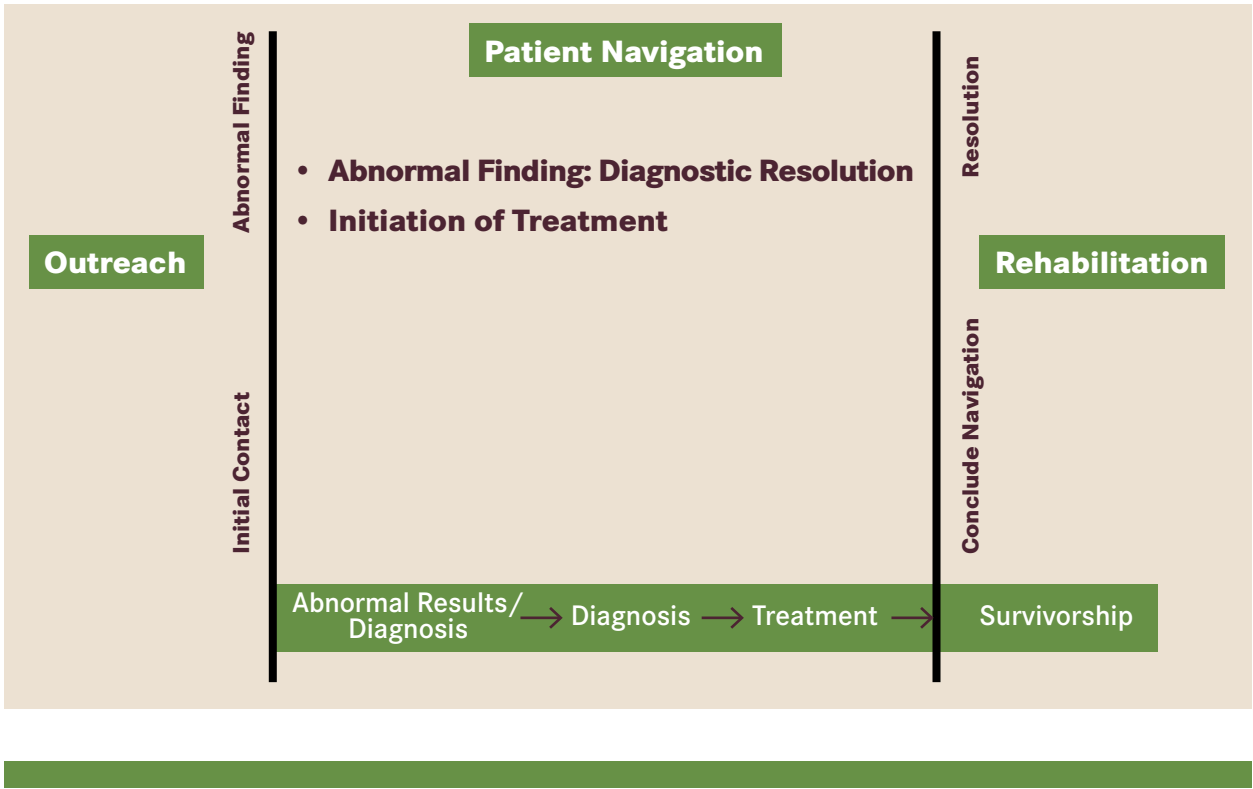
DC's cancer mortality rates are the highest in the country, according to Patierno, with nearly 2800

new diagnoses and 1200 deaths each year; however, the city has no shortage of screening and treatment resources, with 11 hospitals, 4 major medical centers, and several networks of community clinics. So what is causing the city's cancer crisis?

Patierno explained that while DC's quantity of healthcare resources may be satisfactory, equitable access is lacking. DC has a high minority population (58% African American, 10% Hispanic), a great many of whom are medically underserved. Patierno identified several barriers to access for these populations, including inadequate primary care, screening difficulties, an information deficit, lack of insurance, poverty, fear and medical mistrust, cultural barriers, and difficulty navigating DC's healthcare maze.

A geographic barrier also contributes to the city's healthcare disparity. DC consists of 9 wards, 2 of which are separated by the Anacostia River. These 2 wards, which contain high minority populations, are cut off from the city's major healthcare resources. Patierno said a woman from one of these wards may need to take 3 to 5 buses and a subway to reach a mammogram screening site. Situations like these,

FIGURE 1. Framework of Original Patient Navigation Programs



trained) navigators who focused on “structural navigation”—scheduling diagnostic and treatment appointments; arranging financial support, transportation, and child care; connecting patients with culturally sensitive caregivers; and ensuring patients attend their appointments. In general, the lay navigators were able to help patients from suspicious finding to the onset of treatment and could address most of the disparity issues Freeman witnessed. Using lay navigators was also more cost efficient than hiring nurses, giving Freeman the opportunity to start the program and prove its value.

said Patierno, in which underserved individuals cannot overcome access barriers, highlight the tremendous need for patient navigation. Navigators can help deliver quality cancer resources to all members of the urban community.

Control Data

The DC-PNRP control (non-intervention) data revealed opportunities where patient navigation could help alleviate DC’s cancer crisis. Patierno’s GWCI colleague, Heather J. Hoffman, PhD, assistant professor of epidemiology and biostatistics at the George Washington University School of Public Health and Health Services, led a retrospective cohort study of 983 women tested for breast cancer at 6 DC locations between 1998 and 2009. Hoffman’s team examined the effect of race, ethnicity, and health insurance on diagnostic delays in breast cancer.

Background information for the study highlighted DC’s severe breast cancer disparities. Overall, African-American and Latina women present at an earlier age with more aggressive disease than white women do. Additionally, white women have a higher breast cancer incidence rate than African-American women, but African-American women have much higher mortality rates. The researchers had thought that insurance coverage gaps were the root cause of the disparities, and thus were surprised by the actual results.

The data revealed that while having insurance

reduced diagnostic delay time (period between suspicious finding and definitive diagnosis) in African-American and Hispanic women, it did not come close to eliminating their cancer disparities with white women. Diagnostic delay for African-American and Hispanic women with private or government insurance coverage was more than double that of white women with insurance. Patierno noted that a series of other factors—cultural barriers, fear, medical mistrust, etc—must be impacting the delay in diagnosis.

“This is the kind of data that really underscores how important patient navigation is, particularly in racial and ethnic minorities and the medically underserved,” Patierno said. “[Navigators] can address some of the disconnects that lead to these sobering statistics.” He also suggested that the data reveal the expanded healthcare coverage offered through the new federal bill is not a panacea. “To make the assumption that simply having insurance for all is going to alleviate the burden of cancer disparities is a wrong assumption.”

Emerging Concepts in Patient Navigation

GWCI, the headquarters of DC-PNRP, has explored several new concepts in patient navigation.

Integrative Navigation

The early navigation models developed by Freeman (Figure 1) consisted of lay (non-clinically

vamped Freeman’s original model, with clinically trained navigators now guiding patients through primary treatment and beyond (Figure 2). The evolved system also added integrative navigation to structural navigation. Integrative navigation involves a holistic approach that addresses more difficult to define barriers, such as fear, cultural misunderstandings, coping styles, and fatalism. “Many of these issues are particularly challenging to minorities and the medically underserved,” said Patierno.

Longitudinal Navigation

The goal of longitudinal navigation is to provide navigation services throughout the entire spectrum of cancer care, from outreach education to survivorship or end of life care. To provide a seamless transition through the continuum, the longitudinal approach creates navigation subdivisions, including screening, treatment, and survivorship navigators.

Network Navigation

Network navigation builds on the concept of longitudinal navigation. It places the various subdivisions of navigators in a network of strategically placed locations throughout a city. Through their specialties and physical locations, the network of navigators fluidly guides patients through the cancer care continuum and eliminates all access barriers.

GWCI recently received a grant that will greatly enhance its efforts to implement longitudinal and



network navigation. The DC Cancer Consortium awarded GWCI the grant to establish a City-wide Patient Navigation Network that will create a seamless web of coordinated cancer care throughout DC.

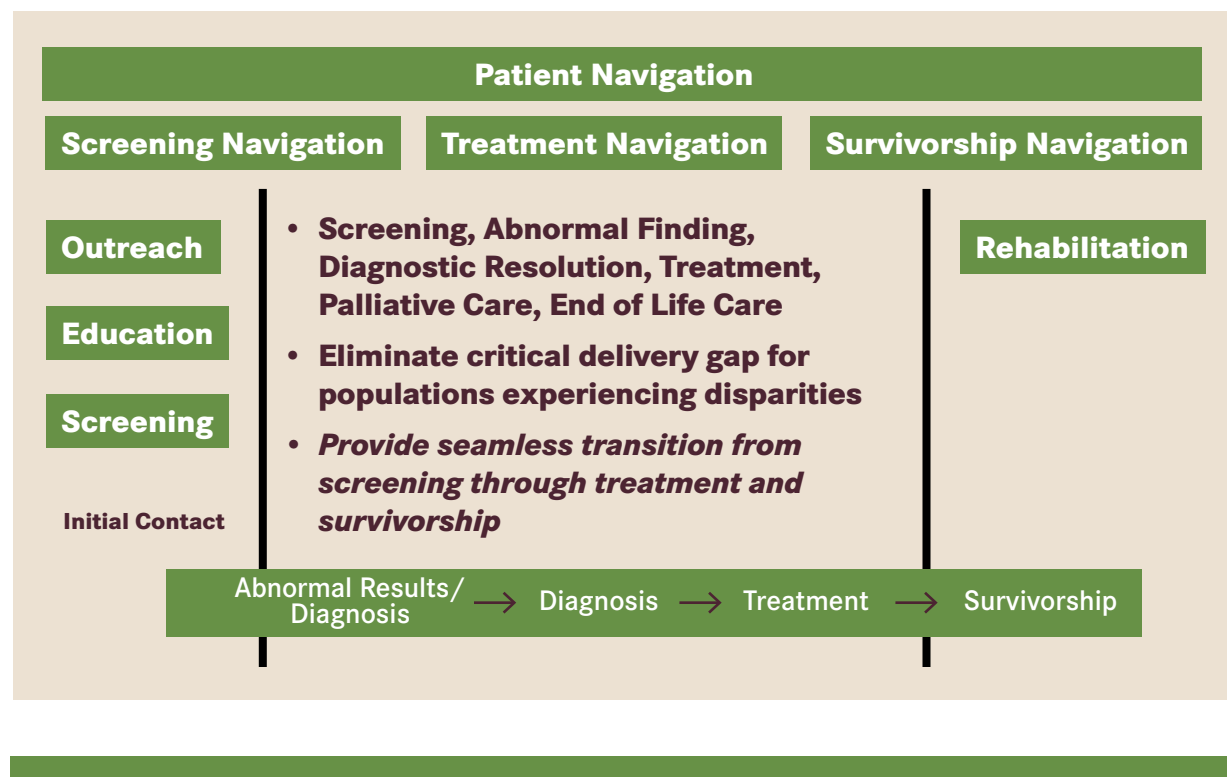
### Rediscovering the Roots of Patient Navigation

Patierno discussed the results of a recent national survey of patient navigators that revealed that more than 95% of the patients being treated were white and, for the most part, insured. While Patierno believes all individuals are entitled to navigator assistance, he is alarmed that “as patient navigation has rolled out across the country, [it has] shifted away from [its] focus on the underserved community.” Studies such as DC-PNRP have demonstrated the tremendous need for navigation in reducing cancer disparities, and Patierno believes it is time for patient navigation to refocus on its beginnings.

Over the past decade, Patierno has traveled around the country with Freeman advocating for patient navigation. Freeman often tells him that “In becoming everything, [patient navigation] risks becoming nothing.” When Freeman began the concept of patient navigation in Harlem, New York, his goal was to address the population’s enormous cancer care disparities. As the definition of patient navigation expands further and further beyond these origins, the navigator’s purpose and value have been diluted.

Patierno said in some cases navigation has become more of a “mentoring” or “buddy” system. It is also used by healthcare systems as a marketing plan to attract patients. To avoid becoming irrelevant, navigators need to work with their healthcare institutions to revisit and carefully define what patient navigation is, and more importantly, what it is not. Patierno insisted navigators must rediscover the roots of patient navigation. He summarized his remarks by concluding, “Keep the navigation focus on overcoming access barriers and this will benefit all, but it will particularly benefit the poor and underserved.”

**FIGURE 2. GWCI’s Framework for Longitudinal, Integrative, and Network Patient Navigation**



## QUICK TIPS FOR NAVIGATORS

At the Second Annual NCONN Conference, Steven Patierno, PhD, executive director, George Washington University Cancer Institute, concluded his keynote discussion with some brief advice for oncology nurse navigators (ONNs) on issues ranging from cost effectiveness to communications.

- Demonstrating that ONNs reduce “no-show rates” for appointments and treatments will make a strong financial case for the importance of patient navigators.
- CFOs calculate cost per square footage in healthcare facilities and clinical space costs run much higher than other areas. For cost viability of ONN programs, navigators should station themselves in the building’s less costly locations.
- When deciding whether or not to use social media, consider staffing and liability issues first. For example, constantly monitoring a Facebook account would monopolize a lot of manpower. On the other hand, if you only sporadically monitor the account, you expose the hospital to liabilities that could arise from neglecting a patient who primarily communicates online. A variety of privacy issues also plague many of the social media networks.
- Text messaging is a good tool for communication because everybody has a cell phone, regardless of socioeconomic status. Unlike with social media, text messaging removes privacy issues because you can use a service that sends the texts but does not have access to private patient information. Also, the terms of the agreement through which patients sign up for the texting service can release you from liability.

# Psychosocial Considerations in Cancer Care

By Eileen Koutnik-Fotopoulos

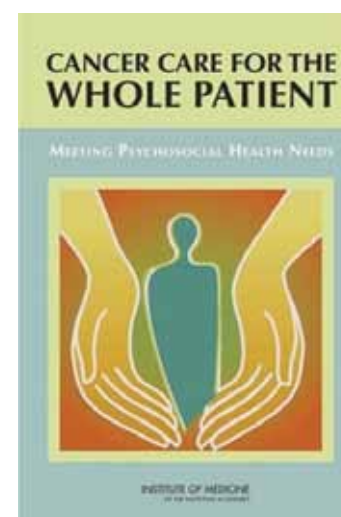
*The Institute of Medicine's 2007 report Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs maintains that a failure to address patients' psychosocial needs can negatively affect treatment outcomes. According to the study, patients' inability to manage the physical, mental, and emotional effects of cancer can impact their response to treatment. The report recommends that all components of the healthcare system involved in cancer care should address psychosocial needs in their policies, practices, and standards concerning clinical care.*



Karen Clark, MS, program manager for the Sheri & Les Biller Patient and Family Resource Center

Psychosocial screening is crucial, according to Karen Clark, MS, program manager for the Sheri & Les Biller Patient and Family Resource Center, Department of Supportive Care Medicine, City of Hope, Duarte, California. Clark discussed psychosocial considerations of oncology patients at the Second Annual NCONN Conference.

Screening communicates to patients and families, "We're a team and really want to partner together in your care," Clark said. The process is also a reliable approach to identify patients who require intervention, develop prospective programs, and anticipate challenges and prevent crises. The process helps identify and triage cancer patients at risk for problem-related distress.



## Cancer Center Study

Clark discussed the 2007 report on psychosocial issues she coauthored, "Problem-related Distress in Cancer Patients Drives Requests for Help: A Prospective Study." The report analyzed data collected using the University of California, San Diego, Moores Cancer Center's 36-question screening instrument, *How Can We Help You and Your Family* (Figure).

Researchers gave the questionnaire to 2071 patients with cancer on their initial visit to the Center. The questions cover physical, practical, social, psychological, and spiritual problems. Patients rated the severity of each problem on a scale of 1 to 5 and circled "yes" if they wanted staff assistance with a particular issue. The top 5 problems given a rating  $\geq 3$  ("high distress") were fatigue (53.1%), sleeping (45.2%), pain (40.4%), finances (35.4%), and understanding my treatment options (33.9%).

Clark told NCONN 2010 attendees that the data "strongly supports the essential role of nurse navigators as the connective tissue of the healthcare system." She added, "These are important issues for you to know as nurse navigators to really help you to understand, problem solve, and connect patients with the appropriate resources."



### SupportScreen

#### Technology at Your Fingertips

Clark helped develop an automated tool, SupportScreen ([www.supportscreen.com](http://www.supportscreen.com)), which can help healthcare professionals assess the entire spectrum of patient needs. The touch-screen system identifies, summarizes, and triages patient biopsychosocial problems in real time. At the City of Hope Comprehensive Cancer Center, patients seen in the outpatient clinics complete SupportScreen as the standard of care before meeting with a physician. SupportScreen provides a systematic approach:

- For patients to communicate with the healthcare team about their physical symptoms and psychosocial problems
- To organize relevant information for the physician and nurse to enhance efficiency of the visit
- To address patients' problems for research and dissemination purposes

SupportScreen is designed with a large font and buttons because "we understand the average cancer patient is over the age of 55 and we want to make it as simple as possible," Clark explained. The technology also has been tested with geriatric patients. "They told us it's almost easier than having to fill out all the forms in the hospital," said Clark.

Depending on the patient's answers, SupportScreen generates 5 potential outputs in real time: 1) summary report for the physician; 2) tailored, written educational information for patients; 3) personalized resources for patients; 4) criteria-driven referrals to professionals and community-based resources; and 5) individual patient responses recorded into a database for analysis.

Each button on SupportScreen is linked with an action. If a patient requests to *Talk with a Member of the Team*, SupportScreen emails the navigator to follow up with a patient who needs to discuss coordination of care.

#### Benefits of SupportScreen

The system benefits patient and families as well as the healthcare team. The benefits for patients and families include:

- Provides a user-friendly electronic interface
- Teaches patients about common problems
- Identifies barriers of care
- Prioritizes immediate needs
- Improves quality of care

For the healthcare team, the benefits include:

- Increases control over the clinical encounter
- Enhances communication and trust with the patient
- Reduces time needed to anticipate and manage barriers to care
- Automates and prioritizes problems
- Streamlines triage and referral to appropriate resources.

"This technology brings our healthcare teams closer together," Clark said. "It brings us closer to the patient and not more removed because it allows us to create more efficiency in our care."

*Eileen Koutnik-Fotopoulos is a freelance writer based in Keyport, NJ.*

FIGURE. University of California, San Diego, Moores Cancer Center's screening instrument, *How Can We Help You and Your Family*

Ask at the Front Desk if you would like help completing this form.

Problems	Rating [1-5]	Yes	Problems	Rating [1-5]	Yes
<b>Ability to request to discuss problem with a member of the staff.</b>		Yes	19. Ability to have children	1 2 3 4 5	Yes
		Yes	20. Being an anxious or nervous person	1 2 3 4 5	Yes
		Yes	21. Losing control of things that matter to me	1 2 3 4 5	Yes
4. Sleeping	1 2 3 4 5	Yes	22. Feeling down, depressed or blue	1 2 3 4 5	Yes
5. Talking with the doctor	1 2 3 4 5	Yes	23. Thinking clearly	1 2 3 4 5	Yes
6. Understanding my treatment options	1 2 3 4 5	Yes	24. Me being dependent on others	1 2 3 4 5	Yes
7. Talking with the health care team	1 2 3 4 5	Yes	25. Someone else totally dependent on me for their care	1 2 3 4 5	Yes
8. Talking with family, children, friends	1 2 3 4 5	Yes	26. Fatigue (feeling tired)	1 2 3 4 5	Yes
9. Managing my emotions	1 2 3 4 5	Yes	27. Thoughts of ending my own life	1 2 3 4 5	Yes
10. Solving problems due to my illness	1 2 3 4 5	Yes	28. Pain	1 2 3 4 5	Yes
11. Managing work, school, home life	1 2 3 4 5	Yes	29. Sexual Function	1 2 3 4 5	Yes
12. Controlling my anger	1 2 3 4 5	Yes	30. Recent weight loss	1 2 3 4 5	Yes
13. Writing down my choices about medical care for the medical team and my family if I ever become too ill to speak for myself	1 2 3 4 5	Yes	31. Having people nearby to help me or needing more practical help at home	1 2 3 4 5	Yes
14. Controlling my fear and worry about the future	1 2 3 4 5	Yes	32. Nausea and vomiting	1 2 3 4 5	Yes
15. Questions and concerns about end of life	1 2 3 4 5	Yes	33. Substance abuse (drugs, alcohol, nicotine, other)	1 2 3 4 5	Yes
16. Finding community resources near where I live	1 2 3 4 5	Yes	34. My ability to cope	1 2 3 4 5	Yes
17. Getting medicines	1 2 3 4 5	Yes	35. Abandonment by my family	1 2 3 4 5	Yes
18. Spiritual Concerns	1 2 3 4 5	Yes	36. Any other Problems you would like to tell us about (please specify):	1 2 3 4 5	Yes



# Reimbursement for Nurse Navigation: It Can Be Done

By Eileen Koutnik-Fotopoulos

*Cancer centers and institutions are embracing the role of nurse navigation as part of the changing environment of oncology care. Unfortunately, formal reimbursement for nurse navigation services is lacking.*

At the Second Annual NCONN Conference, Matthew Farber, MA, director of provider economics and public policy for the Association of Community Cancer Centers, discussed methods for reimbursement.

Currently, navigation is done essentially without reimbursement and how it is funded varies. Hospitals and cancer institutions are funding navigation from general operating budgets, charitable donations, and government and industry grants. Furthermore, hospitals and cancer centers participating in the National Cancer Institute Community

Cancer Centers Program are using grant money for navigator programs. These institutions will be responsible for funding programs after the grant money expires.

## Formal Reimbursement

A valid current procedural terminology (CPT) code is needed for formal reimbursement for nurse navigation. “Right now there is no set reimbursement code that you’re writing down or no set modifier that you add to a CPT code that identifies the work you’re doing,” explained Farber.

CPT codes are assigned a relative value unit (RVU) to determine the amount of work associated with the code. RVUs are assigned by the American Medical Association’s RVS (Relative Value Scale) Update Committee (RUC). To get a new CPT code, an application needs to be submitted to the CPT Editorial Panel & Advisory Committee. Because codes are updated January 1 of each year, it takes a year to find out if a new code is granted. Certain criteria must be met for the committee to consider a new code. If the editorial panel approves the request, it then moves onto RUC for valuation.

“For the application, the key is to demonstrate that the service is distinct and differs from other services already being offered,” Farber advised. “It’s important to be very clear on how this is a unique service.”

Working with advocacy organizations is also prudent, as well as attending the CPT Editorial Panel & Advisory Committee meeting. “Attend the meeting when they’re talking about your application. This can be vital if they have questions [because] you can be the expert they turn to,” said Farber.

## Appeal to Congress

Cancer organizations have been instrumental in getting bills introduced to improve the delivery of cancer care. Farber cited 2 examples: the Assuring and Improving Cancer Treatment Education and Cancer Symptom Management Act of 2009 (HR 1927) and the Comprehensive Cancer Care Improvement Act of 2009 (HR 1844). Congressional action on these bills is unlikely this year, noted Farber.

“Nothing is really going to happen this year because everyone in Congress is tired of talking about healthcare. We just passed this massive healthcare reform bill so Congress wants to talk about something else or doesn’t want to spend any more money.”

Although the newly passed Patient Protection and Affordable Care Act (section 3510) would extend patient navigator programs for 5 years at \$4 million a year, Farber said it will not be continued next year because the money was not appropriated for it.



Matthew Farber, director of provider economics and public policy at the Association of Community Cancer Centers



If institutions want navigation legislation passed, they should find a champion in Congress to introduce the bill. Farber said much of the initial legwork falls on the group wanting the legislation and their ability to rally members to get involved.

**Seek Private Payers for Reimbursement**

Efforts are under way to have private payers reimburse for navigation services. “You really have to promote how nurse navigation services and patient navigation services can promote quality of care for patients,” said Farber. “Also payers not only want to do this, but many want to show they’re promoting quality of care while keeping costs down.”

One way of keeping costs down is bundled payments for episodic care. In order for nurse navigation services to be included in bundled payments, “You need to be vocal and communicate with these private payers and third-party payers that this is an integral part of oncology care and without this the patient wouldn’t have this good quality of care,” said Farber.

In addition to provider advocacy organizations, patient advocacy organizations can benefit reimbursement efforts by mobilizing patients to talk about the importance of these resources—especially when speaking with Congress and government agencies. “Not only do your patients love you, but they will speak on your behalf and advocate for you,” Farber said.

“There are opportunities to get reimbursed. It’s a long process and there are no guarantees. Don’t get discouraged if it doesn’t work out the way you want it,” said Farber. “I know there are a lot of people who support navigation. This is an integral part of cancer care and it’s only going to grow in the future.”

*Eileen Koutnik-Fotopoulos is a freelance writer based in Keyport, NJ.*

## Glossary of Reimbursement Terms

**AMA:** American Medical Association; organization that establishes current procedural terminology (CPT) codes needed for reimbursement.

**AMA Relative Value Scale Update Committee (RUC):** The American Medical Association expert panel that makes relative value recommendations concerning CPT codes to the Centers for Medicare and Medicaid Services.

**Current Procedural Terminology (CPT) code:** Number assigned by the American Medical Association to every medical procedure or service. Insurers use the uniform codes to determine the reimbursement amount they will distribute to a healthcare provider.

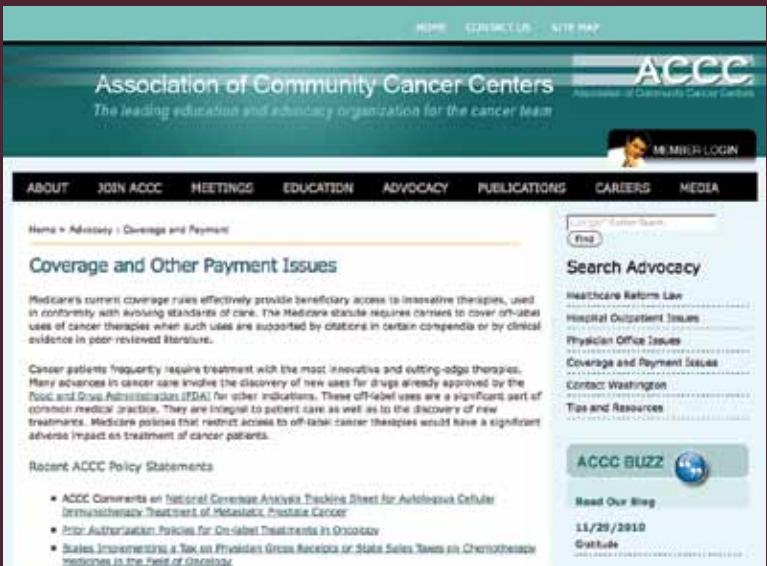
**Patient Protection and Affordable Care Act (HR 3950):** Federal healthcare bill passed by Congress in 2010 that significantly changes distribution and payment for healthcare services in the United States.

**Relative Value Unit (RVU):** Measurement of the amount of work associated with a CPT code. Payment for each CPT code is determined by its RVUs.

**Resource-based Relative Value Scale (RBRVS):** A standardized payment schedule for medical services in which payments are based on the costs of the resources used to provide a specific service.

## ASSOCIATION OF COMMUNITY CANCER CENTERS

The NCONN 2010 presentation on navigator reimbursement was led by Matthew Farber, director of provider economics and public policy at the Association of Community Cancer Centers (ACCC). According to its Website, ACCC is dedicated to “promoting professional learning opportunities and to providing a forum for members to network and enhance their skills in the business, clinical, and management aspects of care for the cancer community.” ACCC membership includes medical and radiation oncologists, surgeons, cancer program administrators and medical directors, pharmacists, oncology nurses, oncology social workers, and cancer program data managers. The organization’s Website provides an entire section dedicated to oncology patient navigation. The site also describes the impact of federal healthcare reform on cancer care. ACCC members can access a slideshow covering the major provisions of the healthcare legislation. Regarding reimbursement specifically, the “Coverage and Other Payment Issues” section of the site aggregates the ACCC’s policy statements on a variety of coverage subjects.



# Integrative Medicine and Cancer Treatment

By Eileen Koutnik-Fotopoulos

*Linda A. Lee, MD, director of the Johns Hopkins Integrative Medicine & Digestive Center (JHIMDC) in Lutherville, Maryland, believes that an integrative approach to treating conditions and symptoms helps improve patients' quality of life. At the Second Annual NCONN Conference, she described the origin of her interest in holistic treatment.*

*Several years ago, Lee, who is board-certified in internal medicine and gastroenterology, was primarily seeing patients with chronic problems and felt improperly equipped to help them. "I felt very limited in how I had been trained. I began to learn and reach out to other healthcare providers to find out what they brought to the table regarding how to help our patients achieve a better quality of life."*



Linda A. Lee, MD, director of the Johns Hopkins Integrative Medicine & Digestive Center

## Integrative Medicine: A Primer

Integrative medicine integrates the best scientific medicine with a broader understanding of the nature of illness, healing, and wellness. This practice makes use of all appropriate therapeutic approaches and evidence-based modalities to achieve optimal health and healing, Lee explained.

She also pointed out that integrative medicine “doesn’t reject conventional medicine, but seeks to enhance it.” Further, while Lee is a strong supporter of integrative medicine, she doesn’t uncritically embrace all alternative practices.

## JHIMDC

Lee’s center in Maryland, JHIMDC, is a multidisciplinary clinic for patients. Along with using the best therapies available to treat a variety of medical conditions and symptoms, the staff incorporates nutrition and other healing modalities to improve symptoms and outcomes. Medical services include acupuncture and Chinese medicine, digestive health services, integrative psychotherapy, nutrition consultations, and therapeutic massage.

“When a person comes to our center, we spend a lot of time educating the patient. We want them to be an active participant in their healthcare,” Lee said. The emphasis is on an individualized approach that considers a patient’s beliefs, values, and concerns.

## Cancer and Integrative Medicine

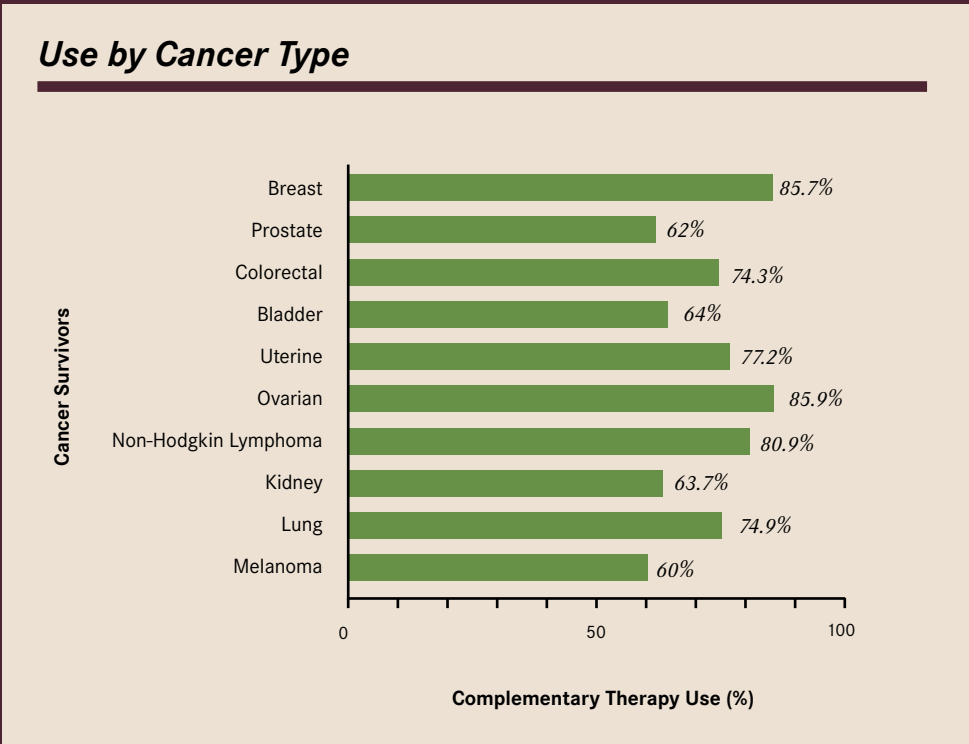
Cancer patients frequently deal with chronic issues. For example, breast cancer patients can experience weight gain and loss, fatigue, menopausal symptoms, psychological distress, and lymphedema. Integrative medicine may help these patients, but finding evidential support for the nonstandard therapies can be challenging.

“There is evidence if you look for it,” Lee said. “It’s very hard to find evidence for integrative medicine therapies in our standard medical journals. While the medical literature is full of reports, it takes time to sift through, find, and weigh how reasonable [a therapy] is.”

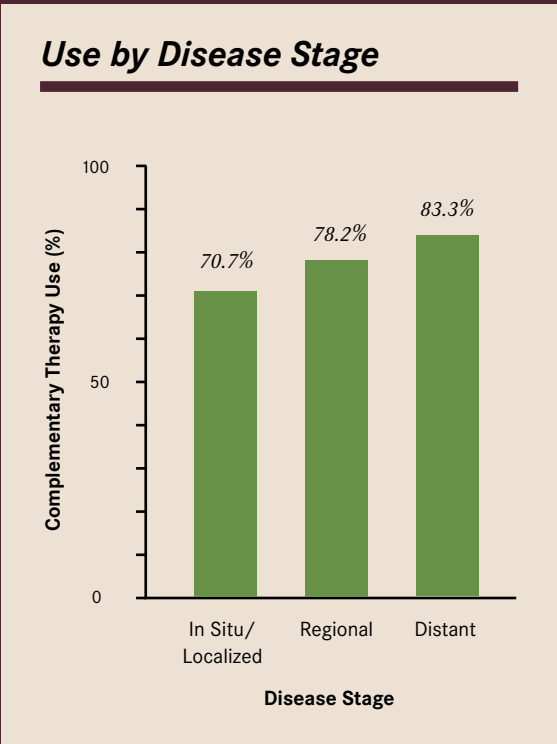
Lee highlighted a study by Walker et al (<http://bit.ly/gz4Y45>) published in the *Journal of Clinical Oncology* that examined acupuncture for vasomotor symptoms in 50 patients with breast cancer. Patients were randomized to either 12 weeks of acupuncture (n = 25) or venlafaxine (Effexor) (n = 25). The results showed that acupuncture was as effective as venlafaxine in reducing hot flashes. Patients receiving acupuncture also experienced no adverse effects (AEs), compared with 18 incidences of AEs in the venlafaxine group. Within 2 weeks of discontinuing drug therapy, the venlafaxine group experienced significant increases in hot flashes, whereas hot flashes in the acupuncture group remained at low levels.



# Integrative and complementary techniques are becoming more commonplace in cancer treatment.



**Reference**  
Gansler T, Kaw C, Crammer C, Smith T. A population-based study of prevalence of complementary methods use by cancer survivors: a report from the American Cancer Society's studies of cancer survivors. *Cancer*. 2008;113(5):1048-1057.



## Safety of Therapies

Integrative therapies are safe when used appropriately, Lee informed NCONN attendees. She specifically mentioned that acupuncture needles do not cause significant bleeding, even in patients with low platelet counts or at risk for increased bleeding, and modified therapeutic massage (oncology massage) can be done safely in patients with cancer who have undergone surgery.

Lee noted the importance of educating patients on integrative therapy use, particularly dietary supplements due to their popularity. “Eighty percent of cancer patients you’re seeing use dietary supplements. Cancer patients love dietary supplements,” Lee said. She then described situations when specific supplements should be avoided.

Patients should not use probiotics if they have a central line (a tube inserted in the patient to administer treatment) and should avoid antioxidants during radiation or some forms of chemotherapy, Lee advised. “If they’re actively getting radiation or chemotherapy, I tell patients taking antioxidants at this time it is probably not a good idea because theoretically it can counteract what radiation and chemotherapy do,” she said.

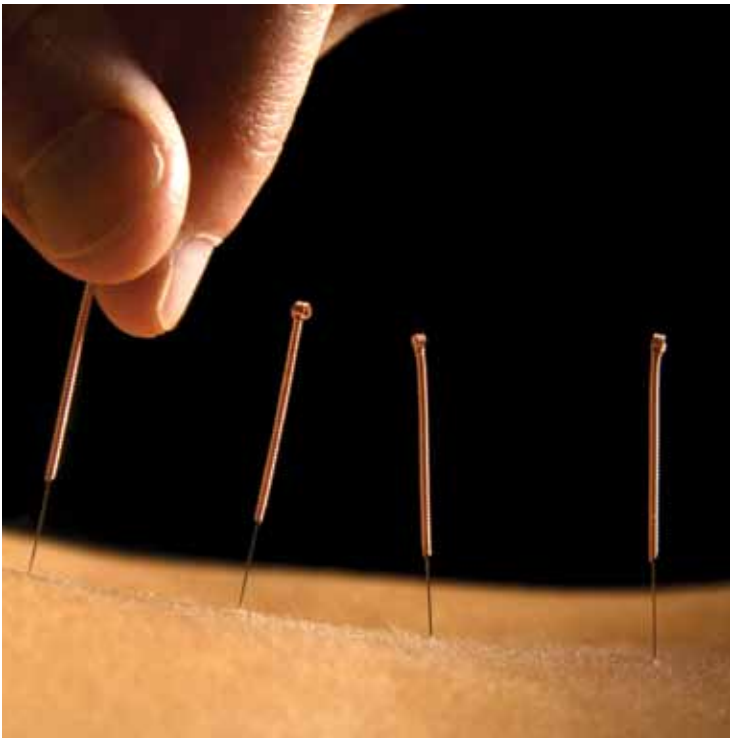
## Challenges to Integrative Medicine

Lee described the challenges healthcare professionals face with integrative medicine.

- Many healing practices still lack scientific data
- Conventional practitioners lack knowledge about traditional healing practices and practitioners
- Current healthcare reimbursement favors procedures and pharmaceuticals over education and face-to-face time with patients

Integrative medicine has made Lee’s clinical practice incredibly satisfying. “I am no longer dependent on just looking at pharmaceutical options for my patients. I have a whole array of modalities and people to help me care for my patients. Integrative medicine has allowed me to become a healer, not just a prescriber of drugs.”

*Eileen Koutnik-Fotopoulos is a freelance writer based in Keyport, NJ.*



# THE NCONN ESSAY CONTEST

*Recognizing Oncology Nurse Navigators*

To acknowledge the work of outstanding nurse navigators, NCONN held an essay contest prior to its Second Annual Conference. Participants were asked to describe how they or someone they know has impacted a patient's or family member's cancer care experience through their role as an oncology nurse navigator (ONN). NCONN's executive board evaluated the submissions and awarded scholarships covering conference costs to the ONNs who best demonstrated excellence in cancer care. Here are the winners.



Dawn Barringer, RN, BSN  
(right), With Kathleen  
Gamblin, RN, BSN, OCN®

## Dawn Barringer, RN, BSN

### Breast Health Navigator

#### Cancer Centers of North Carolina

*(Written on her behalf by her patient, Deborah L. Glaberman)*

I started 2009 with a visit to my gynecologist with a lump I had detected. Thankfully, she was proactive, and less than a week later, I was diagnosed with Grade 3 breast cancer. On January 26, I had a double mastectomy. Since the hospital nurses and trauma doctor made 26 futile attempts to thread the IV prior to my surgery because my veins were playing hide-and-go-seek, I had a port inserted a week later. Less than a week after that, I received word that symptoms undetected by my gastroenterologist for almost a year were diagnosed by my gynecologist as a watermelon and a cantaloupe growing on my ovaries. I had ovarian cancer! Less than a week later, I was on the table again, this time for a hysterectomy!

Somewhere in between all that, I met my oncology nurse (aka: breast navigator), Dawn Barringer. During my first office visit, she presented herself as a petite woman, with a glowing smile. Dawn appeared to be outgoing and genuine. I liked Dawn from the get-go and we really hit it off. She laughed at my nervous jokes. She provided me with information about my illness. She offered words of encouragement, and reassured me that I would be around for my son's wedding months away.

She encouraged me to attend the chemo class that

she and her colleagues offer at the CCNC [Cancer Centers of North Carolina]. Needless to say, I did learn a lot from Dawn that day and every day I have seen her since. She checked up on me when I was sitting in that chemo chair for countless hours. She reminded me that "I may have cancer, but the cancer does not have me!" She remains just a phone call away, and will answer the zillions of questions that pop into my mind. She has always been patient and kind—not just with me, but with everyone I have witnessed her work with. In addition to her superior communication skills, Dawn mixes in compassion, caring and nurturing to provide her patients with exceptional care.

She holds a balance between facts and funny, conferencing and kibitzing. Her positive outlook and wonderful sense of humor are welcome additions to the state-of-the-art knowledge and skills she possesses. Dawn has been by my side through difficult times and happy times. She has held my hand and hugged me when I cried, she has laughed with me over silly circumstances, she has read me the riot act when necessary, she has sat and looked through my son's wedding album with me. She has called me out of the blue, just to check in (even when I was under the care of my ovarian oncologist). She

has invited me to stop by the office when I was in the neighborhood just to see me (and my newly acquired hair) without a doctor's appointment. Most importantly, Dawn has made me feel like I am not just another chart. She has taken a vested interest in me and my family, and she has made me feel very special.

Dawn is a consummate professional. Despite having to work in a field that exposes her to people with terminal illnesses, and dealing with the deaths of patients she has come to bond with, it is obvious that she loves what she does. It does not seem like it is a job to her—helping cancer patients is her passion. It takes a special person with considerable inner strength to help cancer patients through their journey, and Dawn is an expert at helping navigate through the intricacies and bumpy roads along the way.

These days I am in remission, so appreciative to still be alive, and anxiously awaiting our other son's wedding in October! My journey thus far has indeed been an enlightening one. I know there are so many worthy dedicated professionals out there, but in my mind and in my heart, Dawn is by far the best oncology nurse there is.



“As an oncology nurse navigator, I am privileged to be in the position to provide the education and assistance needed to empower patients and their families to make sound treatment decisions.”

Pamela Schroeder BSN, RN, OCN® (center),  
With Anne-Marie Williams, RN, BSN, CBCN  
(left), and Kathleen Gamblin, RN, BSN, OCN®

## Pamela Schroeder, BSN, RN, OCN®

### Patient Navigator

*Regional Cancer Center  
Fort Myers, Florida*

#### Navigator 911

An out-of-state family member called me stating frantically, “They think my dad has cancer.” It was explained the patient had complications from a bronchoscopy and was just admitted to our hospital. The patient’s son and two daughters were making arrangements to fly down and assist their elderly parents.

The very next day, I met with the patient’s spouse and all their children. I discussed and provided written information on lung cancer in general (lung anatomy and cancer staging, how it is diagnosed, and general treatment options along with questions to ask the doctor). I knew the family had time constraints and were worried about having to return home with things very unsettled. They all wanted to be present for the initial appointments and treatment planning.

I scheduled the patient to see the various doctors he had been referred to while in the hospital.

I assured them that the appointments were conveniently arranged—one immediately after the other—as time was of the essence. Although these appointments were scheduled with outside organizations, they were all located in our Regional Cancer Center. I was able to give the family a tour of the facility as well as the doctors’ offices for their upcoming appointments. I assured the patient’s loved ones that each office would have the required records, and I scheduled diagnostic tests that were needed prior to the initial visits. All of this was accomplished within 3 business days of the original phone call.

Finally, I met the patient on his appointment day, and he expressed gratitude for my assistance. He stated, “I understand you were instrumental in getting all of this done and I appreciate the support you have given to me and to my family.” I continued to assist the patient and his family through his entire treatment process. His daughters would call time to time from out of state with questions or concerns.

They felt better about returning home knowing their parents had a navigator to call for support. Some of the comments made by the family were: “You calmed our fears and helped us take control,” “Thank you for the time you spent and the information you provided us was invaluable,” and, “Knowing the sequence of events ahead of time was very helpful.”

As an oncology nurse navigator, I am privileged to be in the position to provide the education and assistance needed to empower patients and their families to make sound treatment decisions. Navigators are a catalyst in helping patients find the confidence to take control of and cope with their disease. For many, the road ahead can be treacherous and does not always lead to a happy ending. I feel accomplished if I can assist in making the cancer journey a little easier. The oncology navigator is like a 911 operator—assessing the situation, instructing to remain calm, calling for reinforcements, and pointing out the next step.



## THE NCONN ESSAY CONTEST

*Recognizing Oncology Nurse Navigators*

“Mari exceeds the performance standards for her position, and as our first nurse navigator at the Cancer Center, she has had to develop the program. Our cancer patients absolutely love her.”



Mari Damhof, RN, OCN® (right), With  
Anne-Marie Williams, RN, BSN, CBCN

## Mari Damhof, RN, OCN®

### Nurse Navigator

*Willmar Regional Cancer Center  
Willmar, Minnesota*

*(Written on her behalf by Barbara Hoeft, director, Willmar Regional Cancer Center)*

It is with great pleasure that I find myself writing this letter recommending Mari Damhof, RN, OCN®, as an exceptional nurse navigator. I am the director of the Willmar Regional Cancer Center, and Mari is our very first nurse navigator. Mari is an outstanding employee who on a daily basis goes “above and beyond” in her role as nurse navigator and is a vital member of our cancer center team. Mari exceeds the performance standards for her position, and as our first nurse navigator at the Cancer Center, she has had to develop the program. Our cancer patients absolutely love her.

To begin with, Mari came with a vast amount of oncology/nursing knowledge, having been a chemotherapy nurse, radiation oncology nurse, and worked on a burn unit and on an adult healthcare floor. Mari cares about the patients and goes out of her way to help them through their journey of cancer.

One example of Mari’s role as an exceptional nurse navigator is the time a patient was seen in the Emer-

gency Department (ED) of our hospital. The ED physician called and wanted Mari to talk to this patient because of the cancer diagnosis. Even though this patient was not one of our cancer center patients, Mari called her to ask if she had any questions and helped walk her through her diagnosis. Mari gave her personal cell phone number to the lady and encouraged her to call at any time. The patient went to another facility for tests and her complicated surgery, but still called Mari to ask questions about the procedures and other questions because she felt that Mari was caring and compassionate about what was happening to her.

When this lady returned home from her surgery that removed the cancerous lesion from her spine, she insisted that the doctor who performed her procedure have his nurses call Mari. Two days later, her husband called Mari with concerns about his wife’s anxiety and that he needed to get baby shampoo for her. Mari made a house call to this patient and her

husband and brought the baby shampoo that she paid for on her own. Three months later, the patient jokes with Mari that she still owes her money for the baby shampoo.

And that is what Mari is. She is our “Go-To” person—the person that patients feel comfortable talking to and, more importantly, the one they can ask questions. Cancer patients have lots of questions, and most times they do not know who to ask the questions to, or even what to ask.

I see Mari’s role as nurse navigator as the key to the success of our cancer center. Because of our financial limitations at this time I was not able to provide assistance for Mari that would have allowed her to go to this conference that I know she wanted to go to. She is a valuable asset to our cancer center team, and I highly recommend her being able to attend the Second Annual NCONN Conference: Changing the Face of Cancer Care.

## Quality of Life Study and the Role of Nurse Navigators

By Jason M. Broderick

At the Second Annual NCONN Conference, Anna Cathy Williams, RN, BSN, PHN, discussed the City of Hope Comprehensive Cancer Center's ongoing P01 Quality of Life (QOL) Lung Cancer Study and how it will demonstrate the importance of Oncology Nurse Navigators (ONNs) to cancer care. The study is examining the effect of palliative care intervention (PCI) in patients with non-small cell lung cancer. According to Williams, showing the positive impact of PCI will reinforce the "natural emergence of navigator roles in supporting cancer patients and their caregivers through the complexities of the healthcare system."

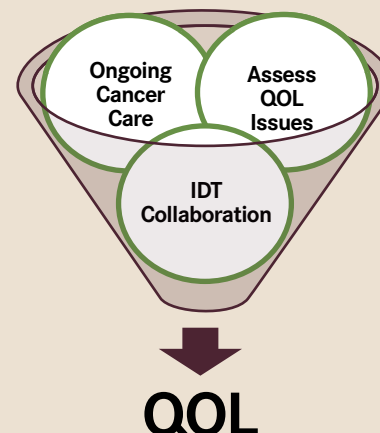
The nearly \$12 million QOL study consists of 3 projects: Early Stage (I-IIIb), Late Stage (IV), and Caregiving. The overall study design comprises 2 phases, with the ongoing phase I consisting of the control arm, and the upcoming phase II being the intervention cohort. Although control and intervention arms often take place simultaneously, the researchers wanted to avoid upsetting patients who were not receiving PCI.

Data in both arms are being obtained through patient and caregiver questionnaires. The Early and Late Stage projects will measure overall QOL, psychological distress, symptoms and symptom management, overall patient function, and patient resource use. The Caregiver project will assess overall burden and QOL, skills preparedness, psychological distress, and resource use

of family caregivers of patients with cancer. Early Stage patients will be followed for 12 months, while Late Stage patients and Caregivers will be followed for 6 months.

Phase II PCI will begin with patient and caregiver interviews assessing the physical, psychological, social, and spiritual QOL issues of patients and their family caregivers. The QOL study's model of care places equal value on these 4 areas, based on survivor feedback and research results from multiple global studies. Once the data are collected, the interdisciplinary team will work on a plan for care collaboration. Final implementation of PCI will involve 4 teaching sessions for patients or caregivers with follow-up phone calls as necessary.

FIGURE. Model of Nurse Navigator Contribution to Patient QOL



QOL indicates quality of life;  
IDT, interdisciplinary team

Williams believes the study's results will show that PCI improves QOL and that QOL enhancement facilitates optimum resource usage for healthcare systems. She also maintains the data will support the ONN role within the healthcare system because navigators contribute to all facets of QOL improvement. Williams even designed a navigator model (Figure) demonstrating how the ONN has a hand in everything the QOL study is trying to accomplish. She praised navigators for being the "single-point person" who helps patients and their caregivers through every step of the cancer care process. "Navigators are on the frontlines. They are the human face that people relate to," Williams said.

## NCONN WRAP-UP

Our coverage of the Second Annual NCONN Conference wraps up in our next issue. Features will cover Matthew Zachary's presentation, "Empowering Young Adults With Cancer" and Dr Michael Krychman's discussion, "Sexual Health and Well-Being: Emphasis on Therapeutics."



Matthew Zachary, founder, CEO, I'm Too Young for This! Cancer Foundation



Michael Krychman, MD, FACOG, executive director, Southern California Center for Sexual Health and Survivorship