Mission

To promote excellence in oncology patient care by fostering collaborative relationships and professional development among oncology nurse navigators and all healthcare disciplines locally, regionally, and nationally

Vision

To be the national leader in establishing standards that define the oncology nurse navigator role by advocating for the oncology nurse navigator within the community and professional arenas

Quarterly Newsletter

National Coalition of Oncology Nurse Navigators

April 2012

DEDICATED TO THE SUPPORT OF THE ONCOLOGY NURSE NAVIGATOR

Funds for ONNs and Relief for Patients

NCONN is pleased to announce the establishment of the National Coalition of Oncology Nurse Navigator patient foundation. Soon active NCONN members will be able to submit a brief application request for funds to assist your oncology patients. Starting May 1, 2012 10% of every member renewal and new member registration fee is deposited in this fund. Once the fund balance reaches $5000 it will be made accessible for members to draw from to assist patients with items and services that they are not currently able to afford or receive. This will be for patients with any type of cancer.

How will you get the money?

NCONN members will be eligible to access this fund for patients if they live and seek treatment in the United States of America and are referred by an active NCONN member Oncology Nurse Navigator (ONN). Recipients of services are identified by ONNs will need to submit a short verification form to NCONN. This verification form will serve as verification that a hospital, community cancer center or healthcare provider as the "nurse navigator" employs you. We are aware that some of you have titles that are not designated as Oncology Nurse Navigators. Once this verification is confirmed the ONN will submit a short online form stating what type of cancer the patient has, what the funds will be used for and the amount requested. Additional information regarding the form and criteria will be announced at a later date. We can assure you that the form will be short and not require financial information from the patient. Additionally, we will ask that the patient complete a short survey.

Giving Model

This fund is modeled after the The Red Devils a 501(c)(3) organization www.the-red-devils.org. That provides funds to local hospital navigators and social workers to disburse to breast cancer patients at their designated hospitals.

Register online now at:

www.nconn.org

The 4th Annual

NCONN Conference

October 4-6, 2012

IN THIS ISSUE

The main difference between The Red Devils and NCONN patient foundation is that we will provide funds for all types of cancer and for patients anywhere in the United States.

This foundation services to improve quality of life for cancer patients and their families. The emotional and physical impact of this disease may make some of the things we take for granted almost impossible.

How You Can Help

- Continue to be an active NCONN member and renew
- Make a contribution
- Encourage individuals to donate to this fund
- Have a fund raiser
- Encourage your facility to donate

Why Should I Give?

Because you will reap the benefits and be able to provide your patients in your communities with the much needed funds that they need to receive care, improve their quality of life and have fun!

Many employers will match employee gifts to the NCONN Foundation. If you need a copy of the IRS letter recognizing NCONN as a 501(c)(3) organization, e-mail info@nconn.org or call 800-581-0175.

Gifts to NCONN are tax deductible to the extent permitted by law.

NCONN
PO Box 1688
Rockville, MD 20849

NCONN tax ID number is 26-1962386

Examples of Items Covered

House cleaning	Transportation to doctor appointments	Transportation to chemotherapy
Transportation to radiation	Financial assistance	Mortgage payments
Rent	Groceries	Eyeglasses
Co-payments	DME supplies	Hearing aide
Physical/Occupational/Speech Therapy	Alternative or Complimentary Therapy	Utilities
Childcare	Wigs	Fun and much more

Navigator Best Practice

EBPH Protocol

Shirley Harvey

RN MSN APN BC-CS OCN

Nurse Navigator

Arlington Memorial Hospital

Mucositis occurs when the mucosa membranes which line the gastrointestinal tract become irritated and inflamed which makes this tissue vulnerable to ulceration and infection. This can be a debilitating effect of cancer treatment leading to several problems including; infection, malnutrition, unintended interruptions in treatment and negatively impact quality of life. Developing a mucositis protocol can provide a proactive approach to try to minimize the impact of this serious side effect.

This evidenced-based protocol is an example of how one person can be the driving force behind implementation of an evidenced-based practice.

PROCESS

Definition of problem:

Multiple mouth rinses were being ordered by physicians with no clear direction to staff on how these rinses should be used or what was effective. There was a great deal of inconsistency.

Nursing staff concerns:

Inconsistency in physician ordering with multiple rinses available

Lack of evidenced based guidelines on what was most effective

Shirley began by reviewing guidelines from the Oncology Nursing Society (ONS). She was fortunate to have been awarded an evidenced based practice fellowship by her facility and selected mucositis as a project.

Shirley coordinated formation of a multidisciplinary team including a physician champion who was a medical oncologist, and representatives from nursing, pharmacy, nutrition, education, research and speech.

Using the information obtained from ONS as a basis for comparison, a literature review was conducted by the team

As per the recommendation of ONS, the team developed a protocol for mucositis care

Validated tools for assessing mucositis were evaluated and the Sonis tool was selected because it incorporated pain and swallowing.

The program was presented to the hospital wide nursing council as well as the unit council and it was approved to implement this protocol system wide.

A hospital-wide education program for mucositis assessment and management was developed.

The education program included physicians as well as inservices for nursing staff, poster presentations and a pre and post test.

As a result of this process, magic mouthwash was removed from the formulary.

Follow up

Some of the physicians were reluctant to follow the protocol. Shirley addressed this from an educational approach by providing the Cochrane Review on mucositis and treatment guidelines from the multinational association for supportive care in oncology (MASCO)

Compliance was monitored initially and appeared to be good.

Mucositis Protocol

The nurse will implement the following protocol based on the patient's clinical condition.

Mucositis Prevention Protocol

The nurses will assess for risk factors at each clinic or infusion visit. The nurse will assess oral mucus membranes using the Oral Mucositis Assessment Scale (OMAS).

1) Cancers of the head and neck
2) Elderly and children
3) Female
4) Altered fluid or nutritional status
5) Exposure to alcohol, tobacco, drugs, oxygen therapy
6) Deficits in self care ability
7) Liver/renal impairment
8) Pre-existing dental problems-poor oral hygiene and dental disease
9) Concurrent chemo/radiation therapy
10) Radiation therapy to the head and neck
11) Dose of chemotherapy agents and administration schedule
12) Mucositis inducing cytoxic drugs.
    i. Bleomycin, capecitabine, cytoxan, cytarabine, dactinomycin, docetaxel, doxorubicin, epirubicin, Etoposide, 5 fluorouracil, gemcitabine, idarubicin, irinotecan, melphalan (high dose), 6 Mercaptopurine, methotrexate, mitomycicn, mitozantrone, paclitaxel, oxalilplatin, vinblastine, Vincristine and vinorelbine.
    ii. Other medications which can contribute to mucositis are antihistamines, antidepressants, antihypertensives, diuretics, opiates, phenothiazines, sedatives and steroids.
    iii. The nurse will obtain a swallow evaluation and dietary referral if indicated.

Basic Oral Care

1) Teach the patient to brush all tooth surfaces for at least 90 seconds after meals and at bedtime. Allow the tooth brush to air dry before storing and change on a regular basis.
2) Remove dentures or bridges if sores exist.
3) Floss at least once daily. Discontinue flossing if the platelet count is <40,000 or the ANC is<1500. If not flossing regularly, do not initiate now.
4) Rinse mouth after meals and at bedtime with a bland rinse of salt, soda and saline or water. 1Tsp soda, 1Tsp salt to 500 mls of saline or water. Take 30 mls of the solution and rinse for 30 seconds and expectorate.
5) Encourage avoidance of tobacco, alcohol and irritation foods (e.g. acidic, hot, extremely cold, rough, and spicy)
6) Use water-based moisturizes to protect lips.
7) Maintain adequate hydration. Encourage frequent sips of water.
8) Teach the family and patients the need for good oral hygiene and a dental referral.
9) Provide written instructions and education to patients regarding oral care. Verify understanding with return explanation and demonstration.

Initiation of cytoxic therapy:

1) Determine treatment related risk factors. Initiate Cryotherapy for patient receiving bolus chemotherapy with short half-life 5 FU or Melphalan. Patients should hold ice or ice cold water in their mouth for 5 minutes prior to the infusion, during the infusion and for 30 minutes after completion of the infusion. Do not initiate for patients who are receiving oxalilplatin.
2) Increase oral care to every 4 hours.
3) Teach the patient and family the treatment related risk factors and the mucositis treatment plan.
4) During therapy:
5) Instruct the patient to continue oral care every 4 hours.
6) Determine patient compliance with mucositis treatment plan.
7) Instruct patient to report any mouth sores, pain, swelling, bleeding and difficulty swallowing or white film.

Mucotoxic Changes

1) Increase oral care to every 1-4 hours for any ulceration or erythema.
2) Assess for secondary infections such as candidiasis and herpes. Consult with the physician and obtain orders for antifungal or antiviral treatment if required. Use antifungal drugs that are absorbed or partially absorbed from the GI track.
3) Consult with the physician for pain management. Ensure adequate pain relief is prescribed to provide for 24 hour coverage. Use of systemic analgesic is recommended in that mucositis is a systemic process. Avoid topical agents such as magic mouth wash, carafate lidocaine and alcohol based solutions.
4) Assess nutritional status. Obtain orders for enteral or parental feeding or for IV hydration.
5) Teach the patient to suck on hard non sweetened candy to stimulate saliva.
6) Determine effectiveness of the intervention.
7) Teach the importance of symptom management.

Recovery

1) Decrease the frequency of the oral care based on the assessment.

Documentation:

1) Record assessments, interventions and evaluation.

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Oral Mucositis Assessment Scale (OMAS)

Patient Name:______________________________________ **Date:** ____________

Location	Ulceration/pseudomembrane* (circle)				Erythema** (circle)		
Upper lip	0	1	2	3	0	1	2
Lower lip	0	1	2	3	0	1	2
Right Cheek	0	1	2	3	0	1	2
Left Cheek	0	1	2	3	0	1	2
Right ventral and Lateral tongue	0	1	2	3	0	1	2
Left ventral and Lateral tongue	0	1	2	3	0	1	2
Floor of the mouth	0	1	2	3	0	1	2
Soft palate/fauces	0	1	2	3	0	1	2
Hard palate	0	1	2	3	0	1	2

Legend:

Ulceration/Pseudomembrane*	Erythema**
0 = no lesion	**0 = none**
1 = < 1cm^2	**1 = not severe**
2 = $1\text{-}3\text{cm}^2$	**2 = severe**
3 = $>3\text{cm}^2$	

Mouth pain

No pain |____|____|____|____|____|____|____|____|____|____| Most severe pain

Swallowing

☐ Normal ☐ Only liquids ☐ Only soft solid foods ☐ No foods or liquids

Lynch Syndrome International

Have you heard about Lynch Syndrome?

Lynch syndrome creates an inherited predisposition to a myriad of inherited cancers and is passed down from one generation to the next, within families. The only method of accurately diagnosing Lynch syndrome is through genetic testing, which is the closest thing to a cure, known today.

The primary mission of Lynch Syndrome International (LSI) is to serve our global communities by focusing on providing support for individuals afflicted with Lynch syndrome, creating public awareness of the syndrome, educating members of the general public and health care professionals and providing support for Lynch syndrome research endeavors.

LSI, an all volunteer organization, is founded and governed by Lynch syndrome survivors, their families, and health care professionals who specialize in Lynch syndrome.

If diagnosed early, we believe Lynch syndrome survivors have favorable outcomes which enhance survival, the longevity and quality of life as well as the emotional well-being of the afflicted.

With the provisions of knowledge, caring and respect for those living with Lynch syndrome, coupled with a common theme of a prevalent positive attitude, we can be change agents, enhancing hope and survivability, impacting the life of countless thousands of people throughout our world.

To learn more about Lynch Syndrome International go to: http://www.lynchcancers.com/

Oncology Nurse Navigators and Community Health Workers: Building Unique Relationships for Cancer Care

Part II of II

Amy Sebastian-Deutsch, DNP, RN, CNS, AOCNS, APN, System Cancer Services
Memorial Hermann Hospital System

Pitching the Collaboration

The February 2011 meeting with Elizabeth Kelley, Ph.D., R.N., CNS-CH, BC-HSP (the driving force for the Houston Community College Community Health Worker Program), was behind me and I had completed the additional research to familiarize myself with Community Health Workers (CHWs). It was now time to try to "pitch" the idea of an affiliation between my hospital system and the Houston Community College (HCC) for the purposes of providing practicum sites for their CHW students. This would include practicum mentorship provided by our own oncology nurse navigators (ONNs). Knowing the size of our hospital system and the fact I wanted to be ready to accept our first CHW students in June of 2011 (only 8 short months after first learning about CHWs), I knew it would not be a small challenge, and yet; I did not think it would be an insurmountable one.

Let me first describe our hospital system. MHHS is the largest not-for-profit healthcare system in Texas and was recognized this year by Thomson Reuters as one of the top 15 healthcare systems in the United States. We serve the greater Houston community which has a population of nearly 6,000,000 people. We are 21 imaging centers, 19 diagnostic laboratories, 10 surgery centers, 12 hospitals, 8 breast care centers, and 7 American College of Surgeons Commission on Cancer accredited cancer centers (now recognized as an integrated network cancer program). Our academic campus, Memorial Hermann – Texas Medical Center, is part of the largest medical center in the world, the teaching hospital for the UTHSC at Houston and (UTHealth™) Medical School. We are known locally for our Life Flight® air ambulance program which maintains 6 helicopters (including one strictly for pediatrics) and covers those within a 150 mile radius of Houston. We contribute in excess of $300 million annually for uncompensated care and community benefits.

While I envisioned CHW students being mentored by any of our ONNs across any cancer diagnosis, since the existing CHW student cohort was supported in part by the Houston Chapter of Susan G. Komen for the Cure, the need to present my idea to the ONNs who navigated breast cancer patients became my prime area of focus. While I would have liked to open all 7 of our cancer centers up to the program, I knew I needed to first pilot this project at a few sites.

Furthermore, our breast care centers are a separate entity from the cancer centers and while both entities work closely together, they have separate administrative personnel. Therefore, both entities would have to agree on the pilot practicum program.

It was important for me to approach the ONNs first for without their approval, the program would not get off the ground. In April of 2011, I approached the ONNs to discuss the CHW role, the HCC program, and to see who might be interested in being a part of the pilot. Four ONNs conveyed interest. I also spoke both with our attorneys and personnel from HCC to learn about the requirements of affiliation agreements and what changes might be necessary. We would need to add CHWs to the current agreements. Unfortunately, given the time remaining, we could only get three practicum sites up and running.

It then became necessary for me to confer with the Directors of Education to find out about our system requirements for students in clinical settings. While this would be primarily an observational experience, and CHW students would not be performing any patient chart documentation, each student would still be required to complete specific facility orientations (including HIPAA requirements). Prior to that, they would need to obtain required immunizations, a TB test, Hepatitis B test, Drug Screen, Background Check, and be CPR credentialed, all of which would need to be signed off by their school clinical instructor.

The next task was to develop a power point teleconference presentation so as to provide an overview of the proposed pilot practicum. Personnel from the respective institutes were invited to participate. Those invited included the ONNs, Directors of Education, Cancer Service Line Administrators, and Breast Care Center Administrators. The proposed pilot was also presented at the respective facility cancer committee meetings. My objectives for these presentations were to describe: 1) the CHW role, 2) the HCC CHW student program (14 college credit hours including a 2 credit hour practicum resulting in certification by the Texas Department of State Health Services), 3) how they would be mentored by the ONNs, 4) how the practicum would be rolled out at the chosen sites, and 5) to gain agreement to participate in the pilot. The following key points pertaining to the pilot practicum were presented.

- ONNs would not be obligated to take any students.
- Interested candidates would contact me via phone and briefly present themselves and their interests as well as their 1st, 2nd and 3rd choices for practicum locations. They would be told there was no guarantee they would be offered a practicum.
- Selected potential candidates would then be referred to respective ONNs so they could be interviewed for "fit" with the facility and the populations they serve. NOTE: Some of the most positive outcomes have been achieved by CHWs who have worked within their own residential communities.
- Summer practicum would begin in June 2011.
- Students would need to fulfill 224 hours over 12 weeks.
- If selected, students would be mentored by ONNs.
- Students would be rotated through multiple activities: clinic, exams, support groups, cancer treatments, and some of our community resource partner locations.
- Students would be required to complete a project deemed beneficial to the respective site ONN and student.

It's a Go!

With a general consensus obtained to move forward with the pilot practicum program, I contacted Dr. Kelley and indicated we were a "go". I further informed her about the requirements CHW students would need to complete prior to attending the required facility orientations, and sent the required form on for completion by the school instructor. My perception was this was something new for the school as far as CHW student practicums. It seemed that we were the first practicum site to require immunizations, CPR, drug screens, TB/Hepatitis B test and background checks.

She informed me that students interested in completing the practicum portion of the program, would be presented our site as an option during the latter half of May allowing a short 4-6 weeks to interview students, offer them a practicum, have them complete the pre-orientation requirements, and attend the required MHHS "kick-off" session and hospital facility orientations. We initially received about 5-6 queries and accepted 3 students. It was at that point that things started to happen even more rapidly. I contacted the accepted students, ONNs, and instructors and conveyed the date of the "kick-off" session. They were informed of the need for lab jackets, school ID badges to be worn on their lab jackets, and a copy of our dress code was e-mailed to them. This provided the impetus for me to complete our system CHW practicum template based on their 8 core competencies (see Table 1).

Table 1. MHHS CHW Practicum Requirements (Based on 8 DSHS Core Competencies)

Objective/Competency	Learning Activity(ies)	Affirmation via
General Orientation	Attend practicum "Kick-Off" Meeting. Attend facility orientation.	Meeting w/ APN, ONN, Instructors & signatures of APN & ONN/Facility Educator
Advocacy	Visit w/ city/state government official(s). Send birthday card (if applicable).	Signature of legislative aide Copy of birthday card
Capacity Building	Identify patient in need of support ex. Newly diagnosed patient. Provide information/invite patient to support group.	Survivor attends support group; confirmed by social worker or ONN signature
Communication	Observe ONN/PT/MD interaction. Attend support group.	Name of MD/Signature of ONN. Signature of ONN.
Interpersonal Relations	Follow patient across care continuum.	Dates of attendance; signature of ONN
Knowledge base on specific health issues	Observe screening mammogram, diagnostic mammogram, breast biopsy, lumpectomy/mastectomy, XRT, and chemotherapy administration.	Signatures of oncology nurses, mammography techs, MDs, and ONN
Objective/Competency	**Learning Activity(ies)**	**Affirmation via**

Organization	Complete project as discussed w/ ONN.	Project completed/signature of ONN
Service Coordination	Observe with CanCare®, ACS, Project Mammogram, Breast Health Collaborative of Texas & The Rose	Signatures of agency representatives
Teaching	Deliver topic presentation "What is a CHW?"	Topic presented and witnessed by ONN- signature obtained.

It was also now time to contact several of our community partner organizations and explain about the pilot CHW practicum. This was necessary so as to pave the way for future contacts by the ONNs/CHW students when they arranged for on-site time to complete the service coordination component of the practicum; the time for them to learn about community resources available for the community populations they would serve in the future. Students were also asked to complete logs on their clinical experiences and to touch base with their mentors at least weekly.

Results of the First Practicum

All three students completed their practicums. It should be noted that some were more successful than others in their efforts; perhaps based on personal motivation and passion for the endeavor. Two out of three ONN mentors verbalized positive outcomes by their CHW students and one ONN indicated her student did not seem to want to fully deliver on the practicum requirements. One of the three CHW students even gained employment in one of our smaller breast centers. While she was not hired specifically as a CHW, she is working in a satellite breast center and in her present capacity she is able to utilize her skill base to work with patients. The relationship that was built with her ONN mentor during her practicum now provides her the opportunity to refer patients from her remote site on to the ONN for higher level care and support when required. Since this had been our first time to work with CHW students, we knew we needed to process the whole experience with both the school faculty and the ONN mentors "at the table".

The ONNs verbalized they "had been unclear as to just how much they could expect or request of the CHW students and how much they could say if the students did not seem to be delivering on the practicum requirements." Handouts on mentoring were provided by the school. Overall, we believed the first pilot was a success. We decided to continue on with a second pilot practicum however, we needed to make some minor tweaks to the system practicum requirements. We would no longer require students to complete a weekly log as this was considered a duplication of other school requirements.

The Second Pilot Practicum

After finally getting the affiliation agreement signed off for our academic campus located in the Texas Medical Center and meeting with the Manager of Education, we were now prepared to offer a 4th practicum site. During this cycle we received about the same number of requests for practicums from CHW students, however, from a geographic perspective, most the CHW students did not want to be considered for the campus sites we had to offer. Furthermore, during the interviews that did occur, the ONNs indicated they did not note the same level of desire for fulfillment of practicum requirements as with the first pilot practicum CHW students.

We only accepted one student for this rotation and this was at our academic campus. Unfortunately, the CHW student elected to quit her rotation after only 3 weeks (the beginning of April 2012). We have yet to process exactly what occurred but are scheduling a collaborative meeting with the school instructors and all of the ONNs to perform an analysis of our practicum and to discuss how we can continue to build this unique partnership which is still in its infancy.

Possible Future Collaborative Efforts

While the CHW students have initially been focusing on breast health and breast cancer, I can see future students focusing on other tumor site specific areas and being mentored by the ONNs that navigate those specific tumor sites. One example might include lung health and lung cancer with a focus on tobacco cessation. Practicum experiences might include observing bronchoscopies and lobectomies, completing Freshstart® tobacco cessation training, and participating in the Great American Smoke Out. Being able to assist in tobacco cessation efforts with community members might help to improve quit rates. Another opportunity might be the head & neck cancer patient population with an eventual community focus on nutritional needs and/ or body image issues. The possibilities are almost endless.

It is important for CHW students to experience first-hand the entire continuum of cancer care. The benefits are many. Students are able to gain an understanding of the entire care process from screening and prevention through suspicion, diagnosis, treatment, and survivorship. Successful completion of this type of practicum can also assist the CHWs to work collaboratively with hospital based ONNs in the future. A common bond can be built with each understanding the other's role and how collaboration can be of benefit to their mutual populations.

The ONN/CHW student practicum is a segue for future relationships between CHWs and ONNs. It affords the opportunity to eventually extend ONN services provided in the hospital setting (when patients have higher level of care needs), out to the community where the college trained CHW can then manage the lower level needs, thus providing a smoother care transition. By the same token, when members of the community require a higher level of care, the CHW can transition the patient back to the ONN. Forging this relationship can only serve to benefit existing cancer patients and will most assuredly assist future cancer patients.

Interesting Fact:

Two out of three adults in the U.S. and one in three children are overweight or obese.

NCONN is a registered non-profit 501(c)(3) organization

Distress and the Nurse Navigator

Part I of II

Kerrie L. Girard, RN, BSN Clinical Navigator at Banner M.D. Anderson Cancer Center in Gilbert, AZ

Imagine for a moment that you are a young, healthy, vibrant wife and mother who goes to the emergency room for abdominal pain and bloating. You are expecting to have a GI workup and to be sent home with a medication for gastric reflux. Several tests are done; labs, a CT scan of the chest, abdomen and pelvis and a paracentesis to remove the extra fluid that is causing the bloating. The simple ER visit turns into an admission to the hospital for further work up and the outcome is a diagnosis of ovarian cancer with metastasis to the liver. You suddenly change from a woman in control of her health and well-being, to a shocked, frightened, overwhelmed patient who hears the word "cancer" but does not fully understand what it means. Oncology, surgery, chemotherapy, and radiation are words you never imagined in your personal health vocabulary. Your focus shifts from the diagnosis to the prognosis and from thoughts of your own well-being to thoughts of your husband, your children and your career. How stressful would this be?

Think now about being a middle-aged man who has just returned from running a marathon. You and your co-workers at the fitness center that you own and operate are training for a triathlon in 6 months. You go for your yearly check up with your primary care physician and have blood work, a cardiac stress test, a digital prostate exam and a routine physical. Your doctor notices an enlarged prostate gland on exam and subsequently adds a PSA level to the blood work. You leave the office and don't think much about it until you get a call a week later from the medical assistant who tells you that you will need to consult an oncologist for your prostate cancer. You have no family history of cancer, you don't understand what an elevated PSA means and frankly, you don't have time to be sick. All you can think about is how this diagnosis will impact your running and how reasonable it would be to put off treatment until the triathlon is over. How stressful would this be?

Picture yourself being a new grandmother, recently retired after 40 years of working as a professional business woman. You are enjoying spending time with the new baby but seem to feel a bit more fatigued than you are used to. You develop a cold that just seems to linger on. The cold turns into an upper respiratory infection with an annoying cough. You see your family doctor who prescribes an antibiotic. Two weeks after completing the medicine, the cough is still not going away. Suspecting pneumonia, your doctor orders a chest x-ray. When you are called in to discuss the results, a bombshell is dropped that you have suspicious lesions in your lungs. You are referred to an oncologist who orders subsequent tests including biopsies, a PET scan of the chest, abdomen and pelvis and blood work. In the process of going through tests, you develop significant pain in several areas on your spine. When you meet with the oncologist to discuss the results of the tests, you are told that you have non small-cell lung cancer with lymph node involvement and metastasis to the bone. If this wasn't devastating enough, this is the same diagnosis that your husband received less than 2 years ago. You saw him suffer and change from a strong man to a weak, frail individual who left this world much too soon. How stressful would this be?

How stressful any of these situations would be depends largely on the individuals faced with the situation. Ditress is an underestimated, difficult to define, and unique response; how stressful something is for one person does not predict how stressful the same situation will be for another. Distress is however, something that every cancer patient is dealing with. One goal for a successful nurse navigator program is to be able to recognize distress as a condition that plays a large part in the patient's cancer journey. Once recognized, the nurse can help the patient to navigate through the rough patches and help alleviate the distress so that the patient can focus on his or her health and well being while the navigator focuses on everything else. To be most helpful, the nurse navigator needs to recognize quickly, the patient's health and financial concerns, psychosocial needs, coping mechanisms and support system as well as any cultural influences or religious beliefs that may impact care. The nurse navigator has to identify barriers to treatment so that the patient can get the most appropriate care as quickly as possible.

At Banner MD Anderson Cancer Center (BMDACC) in Gilbert, AZ, the nurse navigator program is just getting underway. Since its debut in September of 2011, the program has changed multiple times and the process by which patients navigate through the system, has been a moving target. Initially, the nurse navigator, who is an oncology nurse in a case manager role, would meet the patients after financial services. This would allow the navigator to assist right up front if high co-pays or insurance concerns (such as the requirement of prior authorization) were identified. Meeting ahead of time would also give the nurse and patient time to form a relationship and to build trust in one another. The navigator would be able to assess the support system, the family dynamics and the patient's coping mechanisms. Ideally, the nurse navigator would obtain important information on the initial visit that could be relayed to the appropriate staff such as social worker, dietitian, physical therapist or physician. The nurse would gather treatment information including the patient's understanding of his or her diagnosis and prognosis, the patient's family history of cancer, the patient's past surgery, chemotherapy or radiation treatment and any medical records or scans that the patient may have carried with them.

In theory, meeting the patient prior to him or her seeing the physician was a good idea but every good idea has its drawbacks. BMDACC nurse navigators recognized that too much time was spent with patients that were only getting a second opinion; patients who were not returning for treatment were not going to need the nurse navigator and the time being spent on those patients was time taken away from the patients who really needed assistance.

Meeting the patients ahead of time occasionally made the patients late for the physician visit, causing the patient and physician to feel rushed. The anxiety level of patients facing a cancer diagnosis was so high that a large portion of what the navigators were saying at the beginning was not being heard. We recognized that a different approach was indicated to better provide for the needs of our patients.

Therefore, the nurse navigators switched gears and began seeing the patients after they met with the physician; this allowed the nurse navigator and physician to better communicate regarding the patient's treatment plan and address distress concerns.

Regardless of when the patients are seen by the nurse navigators, at Banner MD Anderson Cancer Center, the distress level of the patient and his or her loved ones is considered very relevant to the treatment plan and to the care received. Any navigator program should address distress as one of its key components in order to be effective. The caring, nurturing and compassionate traits that go along with nursing also need to be incorporated into navigation programs. Cancer patients deserve medical treatment for their cancer and distress relief from their nurse navigator.

Part II on distress will cover screening and management and will be in the next newsletter.

Navigating Breast Cancer Survivorship: Sustaining the Good News

By Ann McCue, RN, BSN, OCN and Robert Fisher, MD

Forty years after the declaration of war on cancer, one of the most profound shifts in cancer care today is a new focus on treating those living beyond cancer as well as those living with cancer.[1] We celebrate the National Cancer Institute report of 2,632,005 women and 13,616 men who have a history of breast cancer and are alive today.[2] Oncology professionals, including nurse navigators, must address the specific needs of breast cancer survivors as their numbers continue to grow. In order for the oncology care community to sustain excellent outcomes for these survivors, there are several important questions to consider.

Will medical oncologists continue to provide long-term breast cancer follow-up care? A recent survey found that 91% of breast cancer patients expect their oncologists to direct their follow-up care. Over the past two years, the American College of Surgeons (ASCO) and the Institute of Medicine (IOM) have released reports that predict a severe shortage of medical oncologists and other oncology-related health care personnel over the next 10-20 years.[3] The expected shortage and ongoing changes to insurance reimbursement models are two factors that may accelerate the transition of breast cancer follow-up care from an oncology specialist to a primary care provider (PCP). It is imperative that PCPs receive the support and education they need in order to provide safe and effective care during this transition.

Are primary care physicians ready to treat breast cancer survivors? A nationwide study of barriers between PCPs and medical oncologists (MOs) revealed several clear themes. Co-sponsored by the National Cancer Institute and the American Cancer Society, the Survey of Physicians Attitudes Regarding the Care of Cancer Survivors was returned by 1,072 PCPs and 1,130 MOs providing care to breast and colon cancer survivors, a 57% response rate.[4] PCPs were more likely than MOs to report ordering tests or treatments primarily as malpractice protection, being concerned about missing care, and lacking adequate training to manage patient problems. MOs were more likely than PCPs to report concerns about duplicated care. They also exhibited less confidence in PCPs' skills to manage breast cancer than the PCPs did themselves. These results highlight the need for greater PCP support and training in breast cancer follow-up care, and the need for oncologists to promote and support that care by providing thorough treatment summaries and survivorship care plans.

How will breast cancer follow-up care be supported? National standards are being discussed but are far from being finalized, so it is vital that evidence-based information about breast cancer follow-up care best practices is available to all stakeholders. In the fall of 2011, medical oncologist Robert Fisher, MD formed a non-profit organization to accomplish this very goal, as expressed in its mission statement: "The Pink Ribbon Survivors Network exists with the dual purpose of serving the needs of breast cancer survivors and the needs of health care professionals that care for breast cancer survivors."[5] The website offers a comprehensive online library that provides information for three primary groups: PCPs, survivors, and oncology professionals, including ONNs. These groups are all represented on the board.

Living Beyond Breast Cancer. In September 2011, the LIVESTRONG organization sponsored a meeting in Washington, D. C. that brought together 150 community leaders, cancer experts, cancer survivors, and their advocates to identify the essential elements of survivorship care delivery. One of the five elements that received unanimous consensus was having a "strategy which addresses care coordination with primary care physicians and primary oncologists."[6] As plans evolve to provide support for breast cancer throughout their lives, oncology nurse navigators must stay informed about the process and know how to access resources that will help make this goal a reality.

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Interesting Fact:

A report from the International Agency for Research on Cancer found that between a quarter and a third of common cancers in the U.S. and other industrialized countries are caused by the joint effects of obesity and sedentary lifestyle.

Results of Winter Survey

1. I would like to see more Oncology Nurse Navigator (ONN) Disease Specific Toolkits?	
Yes 100%	No 0%
2. I would like to work on an ONN toolkit committee.	
Yes 29%	No 66%
3. This is the next ONN Toolkit I would like to see available for NCONN members	
Breast 31%	Prostate 6%
Lung/Thoracic 26%	Blood Cancer's 6%
Survivorship 17%	Melanoma 3%
GI (colorectal) 12%	
4. I will be attending the 4th conference in Nashville.	
Yes 14%	No 16%
Maybe 70%	
5. I want to make a suggestion for the 4th Annual NCONN Conference in Nashville, Oct 4-6, 2012	
Yes 91%	No 9 %

Comments:

- Have Matthew Zachary from Stupid Cancer back
- Offer certification
- Have a recognition ceremony
- Do not make every presentation a power point presentation, have panel members who take questions from the audience.

ONN List-serv

Hot topics

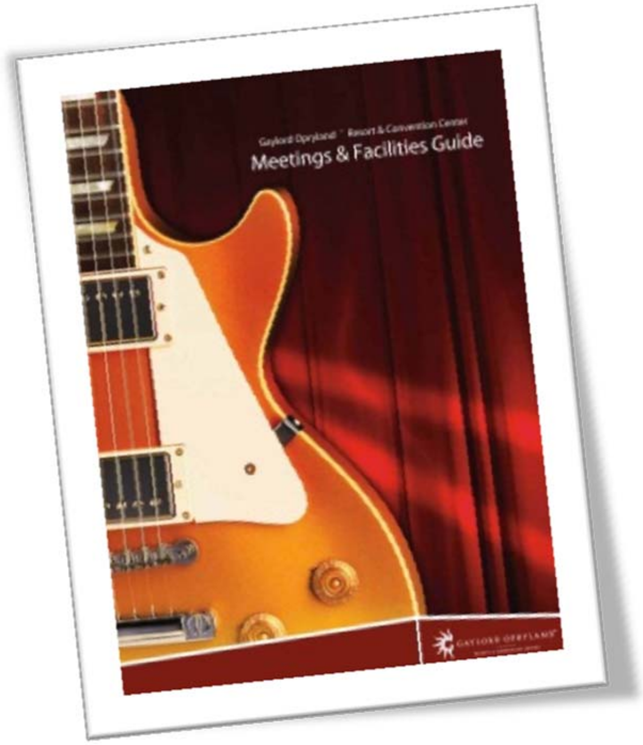
by
ONNlistserv@nconn.org

What is a list-serv?

When e-mail is addressed to a LISTSERV mailing list, it is automatically broadcast to everyone on the list. The result is similar to a newsgroup or forum, except that the messages are transmitted as e-mail and are therefore available only to individuals on the list. To join list-serv, contact lmercier@nconn.org

TOP 10

#1 Distress Tools
#2 Databases
#3 Art Therapy
#4 Lung Cancer Screening
#5 Breast Navigator Model
#6 Mesothelioma
#7 HPV Testing
#8 Lung Navigators in Radiology
#9 NAPBC
#10 Chest CT for early detection



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Spring 2012 Survey

To take the survey, go to *www.nconn.org* or
http://www.zoomerang.com/Survey/WEB22FNYZCJDD4

Questions:

1. How many disease sites do you provide navigation?
2. What disease sites do you navigate? (check all that apply)
3. How many nurse navigators are in your facility?
4. What data do you track? (check all that apply)

Results will appear in the 3rd Quarter Newsletter

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