



Leadership Council

Lillie Shockney, RN, BS, MAS
University Distinguished Service
Associate Professor of Breast Cancer
Administrative Director
Johns Hopkins Breast Center
Associate Professor
Dept of Surgery & Dept of Gynecology
Johns Hopkins University
School of Medicine
Baltimore, Maryland

Sharon Gentry, RN, MSN, AOCN, CBCN
Breast Health Navigator
Derrick L. Davis Forsyth
Regional Cancer Center
Winston-Salem, North Carolina

Jay R. Swanson, RN, BSN, OCN
Oncology Nurse Navigator
Saint Elizabeth Cancer Institute
Lincoln, Nebraska

Susan M. Gardner, RN, CBEC, CBCN
Oncology Nurse Navigator
Valley Medical Center
Renton, Washington

Carol Lewis, RN, BSN, OCN, CRNI
Oncology Nurse Navigator
Memorial Hermann
The Woodlands, Texas

Nicole Messier, RN
Nurse Navigator
Vermont Cancer Center
Burlington, Vermont

Pamela Matten, RN, BSN, OCN
Nurse Navigator
Thoracic Oncology Program
The Center for Cancer Prevention and
Treatment
St. Joseph Hospital
Orange, California

Elaine Sein, RN, BSN, OCN, CBCN
Senior Project Manager
Fox Chase Cancer Center Partners
Rockledge, Pennsylvania

Linda Fleisher, MPH, PhD(c)
Assistant Vice President
Health Communications and Health
Disparities
Fox Chase Cancer Center
Cheltenham, Pennsylvania

Empowering Oncology Nurses

In the past several years, the concepts of patient navigation and survivorship care have come to the forefront in oncology. Given the growing interest in these topics, the Leadership Council of the Academy of Oncology Nurse Navigators has chosen to embark on a path to empower all oncology nurses to enhance their understanding of relevant issues and their ability to implement strategies in patient navigation and survivorship care.

For the remainder of 2010, this publication will run within the pages of *The Oncology Nurse*; in addition we

invite manuscripts on all issues relevant to these two exciting areas within oncology patient care, again in order to expand this publication into a peer-reviewed journal in 2011. For more information regarding submitting a manuscript please e-mail our team at editorial@greenhillhc.com. For your reference, complete author guidelines can be found on page 4.

Thank you for your continued interest in these and other topics critical to improving the care our patients receive and their treatment experience. ●

SURGICAL NAVIGATION

The Role of Patient Navigation in the Breast Surgical Oncology Setting

By Lillie Shockney, RN, BS, MAS

*University Distinguished Service
Associate Professor of Breast Cancer*

Administrative Director, Johns Hopkins Breast Center

*Associate Professor, Department of Surgery & Department of Gynecology
Johns Hopkins University School of Medicine*

Baltimore, Maryland

Breast cancer remains a feared disease among women. The incidence for 2009 in the United States has been estimated at 194,280 individuals.¹ Although treatment has improved over the decades, women still carry an image of the Halsted radical mastectomy when thinking about this disease.

Empowering women with information so that they can actively participate in decision making about their disease is critically important for those diagnosed with breast cancer.² Without appropriate patient education, coordination of care, efficient management of resources, and removal of barriers to care, a patient may blunder through the healthcare system not receiving the treatment she needs to become a survivor.

In many breast centers, navigation begins at the point of diagnosis; in some

breast centers, the breast imaging facility begins the navigation as part of its recruitment process for mammography screening. Whether initiating the navigation process at the time of a screening mammogram or implementing navigation at the time of a diagnosis, providing guidance and direction for a patient with breast cancer can ease her anxiety and help ensure she receives appropriate care in a timely manner.

Step 1: Educate the patient about the roles and responsibilities of the breast cancer nurse navigator

Explain to the patient the functions that will be performed on her behalf. Also provide her information about the rest of the oncology team who will be directly involved in her care. Review the process of how decisions will be made regarding her treatment, and the

order in which the decisions and subsequent treatment will occur.

Step 2: Identify barriers that may affect efficient and effective delivery of cancer treatment

As should be with any initial navigation assessment, interview the patient to determine her needs, identifying any barriers that may impact her ability to receive treatment. These barriers include financial and economic; language and cultural; communication; healthcare system; transportation; bias based on culture, race, or age; and/or fear.³

Step 3: Expedite appointment with the correct oncology specialist

Once breast cancer is diagnosed, an appointment with an oncology specialist is needed to determine the plan of care.

Continued on page 2



**REGISTER TODAY
& SAVE \$200**

First Annual Navigation and Survivorship Conference

September 17-19, 2010 • Baltimore, Maryland

www.AONNOnline.org

The Role of Patient Navigation... *Continued from cover*

To triage the patient appropriately, glean information from the biopsy results and breast imaging studies. Descriptions of the size of the mass and type of breast cancer diagnosed can help in determining the first phase of treatment most likely to be recommended. For example, a patient diagnosed with a 0.8-cm invasive ductal carcinoma that was found on a routine screening mammogram is usually a good candidate for lumpectomy with sentinel node biopsy; therefore, she would need an appointment with a breast surgical oncologist. However, a patient diagnosed with inflammatory breast cancer based on the redness of the breast and a biopsy of the breast skin that showed the presence of cancer cells in the dermal lymphatics would be guided to a medical oncologist for neoadjuvant chemotherapy. The urgency of an appointment is usually driven by the patient's anxiety, not by a change in clinical outcome if her

appointment is scheduled several weeks from the time the diagnosis is confirmed. Ideally, arranging for consultation within a few days will help in reducing her anxiety and fear of the unknown.

Step 4A: Provide educational information to the patient based on stage of disease and anticipated treatment plan

Early on, provide the patient with an overview of what to expect regarding each phase of her treatment. Take care not to overwhelm the patient with information. For example, providing details about the surgical treatment would be appropriate for patients having lumpectomy or mastectomy as their first treatment. Touching on adjuvant therapy and how decisions will be made regarding what adjuvant therapy will be needed is sufficient at the navigation appointment following initial consultation with the doctor. Whenever possible, the navigator

Whenever possible, the navigator should be present with the patient during that consultation so that she has a clear understanding of the information stated by the physician.

should be present with the patient during that consultation so that she has a clear understanding of the information stated by the physician. By doing so, the treatment plan can be accurately reiterated to the patient and family. In addition to verbal consultation, provide information in writing.

Step 4B: Provide emotional support to the patient and family

This disease affects the patient and those who love her; it can be a life-altering experience, whether diagnosed early or at an advanced stage. Providing the patient an opportunity to express her fears, ascertaining her previous knowledge base of breast cancer (particularly any misinformation she may have), and assessing the family's needs should also take place early in the care-delivery process. Whenever possible, provide the patient an opportunity to be matched with a volunteer who is a survivor with training specifically designed to provide support to others newly diagnosed with a similar treatment plan and stage of disease.

The patient may experience anxiety about changes to her body image that will happen as a result of surgery and systemic treatment.⁴ She may also have concerns about job security if she needs to be off from work for an extended period of time. She may be concerned about how to tell her children about her diagnosis. She may also be anxious about her sexuality as well as her chances of surviving this disease.⁵ A variety of resources are available to patients and their families. Even for patients who do not appear to be struggling emotionally, it is helpful to provide them a list of resources in case they wish to access them now or in the future.

Step 5: Schedule the patient for surgery

After the surgical treatment plan is known, arrangements can be made to schedule the patient for surgery. Assess comorbid conditions that may impact surgical management to determine whether an anesthesia consultation is warranted or other special consultations are needed. Immediately notify the patient's primary care physician so that a physical examination and preoperative tests can be conducted, allowing enough time for results to be reviewed before the surgery date. Also review any medications the patient is

currently taking to determine whether any drug (eg, an anticoagulant) needs to be discontinued before surgery.

Step 6: Teach preoperatively

In some breast centers, the nurse navigator will conduct preoperative education classes to prepare a patient for the specific type of surgery she will soon be having. This education may include:

- Drain management
- Wound care/dressing changes
- Body image (photographs to show her immediate incisional appearance and scar healing over time)
- Activities of daily living
- Sexual activity
- Exercises
- Coping with fatigue
- Coping with anxiety/addressing psychological well-being
- Pain management
- Urgent care needs—signs of infection or surgical complication.

The procedures to be reviewed depend on the specific type of surgery the patient will be undergoing. These procedures include wire localization, sentinel node biopsy, axillary node dissection, lumpectomy, mastectomy, skin-sparing mastectomy, insertion of tissue expander, transverse rectus abdominis myocutaneous (TRAM) flap reconstruction, deep inferior epigastric perforator (DIEP) flap reconstruction, superior gluteal artery perforator (S-GAP) reconstruction, latissimus dorsi flap reconstruction, or transverse gracilis/inner thigh (TUG) flap reconstruction.

Step 7: Review preoperative tests and readiness for surgery

Review all preoperative tests to ensure that the patient's laboratory values, chest film, and any other tests are within normal limits and do not require intervention. These can include additional imaging studies that were performed (such as breast magnetic resonance imaging) to ensure that no additional workup is needed that may impact the type of surgery planned.⁶

Step 8: Contact patient and assess after surgery

Some institutions follow a protocol in which the recovery room nurse contacts the patient who had ambulatory surgery; in other institutions, the navigator may contact the patient. If in line with the surgical protocol for the institution, contact the patient the morning after

Continued on page 3

Example of Patient Navigation during Surgical Oncology Care

Action	Date
1. Patient is informed that biopsy is positive for breast cancer	4/1/2010
2. Patient is contacted by nurse navigator	
a. Barrier assessment	
b. Roles and responsibilities	
c. Patient scheduled for consultation with surgical oncologist	4/1/2010
3. Surgical consultation	4/4/2010
a. Patient is educated about surgical treatment plan	
b. Preoperative tests and physical examination are arranged	
c. Scheduled for preoperative teaching	
d. Surgery scheduled	
e. Postoperative appointment with surgeon, 5 to 7 days after surgery	
f. Postoperative consultation with medical oncologist, 10 to 14 days after surgery	
g. Postoperative consultation with radiation oncologist, 15 to 18 days after surgery	
4. Review of preoperative tests	4/12/2010
5. Preoperative teaching performed	4/12/2010
6. Surgery performed	4/15/2010
7. Assessment of recovery process by phone	4/16/2010
8. Postoperative appointment with breast surgical oncologist	4/21/2010
9. Consultation with medical oncologist	4/26/2010
10. Consultation with radiation oncologist	4/30/2010
Barriers identified	Action taken
Transportation for postoperative appointment	Taxi voucher provided



NAVIGATION MODELS

York Cancer Center Takes Team Approach to Patient Navigation

An Interview with Diane McElwain, RN, OCN, MEd, and Deana Albright, MSW, LSW

By Karen Rosenberg

As the role of patient navigator continues to evolve, questions have arisen about the respective roles of oncology nurses and oncology social workers in providing support and guidance for patients with cancer. In this interview, oncology nurse Diane McElwain, RN, OCN, MEd, and oncology social worker Deana Albright, MSW, LSW, of York Cancer Center, York, Pennsylvania, describe the team approach used at their cancer center to provide assistance with their patients' myriad health, emotional, and practical issues.

When and how did you start your navigation program at York?

DM: The cancer center in York was started in 1993. A business director was hired first and she recruited an

oncology nurse and an oncology social worker. Little did we know then that we were actually setting up a navigator program. I was seeing a lot of breast cancer patients at that time and started a breast cancer support group and then also special events for breast cancer patients. It soon became clear that since we see at least 400 breast cancer patients a year, that was a group that needed special attention. We have since hired another oncology nurse—Sue Bowman—to be a breast cancer navigator, but Deana and I continue to navigate other patients. We have also hired another oncology social worker, Kathy Allen. Only Sue has the title of navigator, but we all act as navigators.

The Oncology Nursing Society and the Association of Oncology Social Work (AOSW) recently held a meeting to discuss the respective professions' role in patient navigation. At

your center, how do you divide your responsibilities for patient navigation?

DM: In York, we have a building with three departments: cancer support services, radiation therapy, and a private practice in medical oncology. It is rather unusual to have a private practice integrated within the cancer center, and one of the reasons the medical oncology office decided to come to our building was that we provide extra staff to enhance patient care—the patient navigators as well as a financial counselor and dietitian. At the same time, having the private practice means that there are more oncology nurses added to our team because they have 12 or 15 oncology certified nurses within their practice. A patient may enter through the chemotherapy office and be referred to us for additional services, whether it be a dietitian or a mental health or financial counselor. The same thing happens in

the radiation department; the nurses there refer patients for the services we provide. We have a very fluid system of finding patients without a lot of boundaries, and sometimes more than one team member is working with the same patient.

We do, of course, have some boundaries. I clearly do not handle money issues or mental health. Often it is the nurse who has the initial conversation with the patient and identifies a problem, such as depression or a financial issue, and then we interact with the other navigators based on the patient's needs.

Based on your own experience, do you feel that there is a need for special credentialing for oncology nurse navigators?

DM: There are nurses and social workers who are very skilled in inpatient and outpatient care. I think that if you

Continued on page 4

The Role of Patient Navigation... *Continued from page 2*

discharge from the surgical facility. For women undergoing lumpectomy or mastectomy without reconstruction, this usually is the morning after the ambulatory surgery procedure. A woman undergoing simultaneous reconstruction may be hospitalized 1 to 3 days. If someone other than the navigator contacts the patient, clear communication with the navigator is essential to ensure that information regarding how the patient is faring both physically and emotionally is documented so that the appropriate next steps for coordination of her care can be arranged.

Step 9: Schedule postoperative appointment with the breast surgical oncologist

Ideally, the postoperative appointment should be arranged at the time the surgery is scheduled. During this appointment, the nurse navigator should be present to hear how the pathology results are explained by the surgeon and interpreted by the patient. The navigator should review the pathology results before the consultation to be prepared for questions and determine what follow-up appointments will be needed. The ease of access to appointments with the medical oncologist and the radiation oncol-

ogist will influence the amount of prearrangements needed to deliver care efficiently. For example, if the wait time for a medical oncology consultation is usually 3 weeks, it would be advisable to preschedule the medical oncology consultation by arranging it at the time of surgery. By doing so, the patient can have her surgery, be seen for her postoperative appointment with her surgeon 5 to 7 days after surgery, and be seen by the medical oncologist 10 to 14 days after surgery. Any patient having a lumpectomy or who has known nodal involvement or a T3 tumor should also be automatically scheduled to see a radiation oncologist. In most cases, patients who have drains will be able to have the drains removed at the time of this postoperative consultation as well. Wound care should be reviewed to ensure the patient is keeping the area dry, knows the signs of infection, and has information on wound-healing.

Information from the pathology report to review with the patient should include: size of the invasive portion of the tumor; status of all six margins; grade; Ki-67; presence of angiolymphatic invasion; nodal status; hormone receptors; and human epidermal growth factor receptor type 2. Provide the patient with information

as to how these pathology results will be used to determine the next steps in her treatment.

Step 10: Transition the patient to medical oncology and radiation oncology nurse navigators

In some institutions, the nurse navigator is responsible for the patient across the entire continuum of care. It is more common, however, for a navigator to be responsible for navigating the patient during specific phases of her treatment. In these cases, the initial navigator must provide detailed information to the next navigator who will be responsible for overseeing the patient, starting with the barrier assessment information collected initially.

Clinical outcome may be impacted by adherence to the National Comprehensive Cancer Network treatment guidelines, based on stage of disease and prognostic factors.⁷ The medical oncology navigator should provide the patient with an overview of her role and responsibilities and begin the patient education process as it relates to what to expect at the time of her medical oncology consultation and how decisions will be made about systemic therapy. The radiation oncology nurse navigator will do the same.

Tracking the information collected and the steps taken along the navigation process is important to assess the patient's position across the continuum of care and to help ensure that no delays occur or the patient does not fall through the cracks. This can be accomplished electronically using a software program or via an electronic medical record. If relying solely on a paper process, be sure that this documentation becomes part of the patient's permanent medical record.

References

1. *Cancer Facts & Figures*, 2009. Atlanta, GA: American Cancer Society; 2009.
2. Lally RM. In the moment: women speak about surgical treatment decision making days after a breast cancer diagnosis. *Oncol Nurs Forum*. 2009;36:E257-E258.
3. Shockney LD. *Becoming a Breast Cancer Nurse Navigator*. Baltimore, MD: Jones & Bartlett Publishers; 2009.
4. Biglia N, Moggio G, Peano E, et al. Effects of surgical and adjuvant therapies for breast cancer on sexuality, cognitive functions, and body weight. *J Sex Med*. March 2, 2010. Epub ahead of print.
5. Fallowfield LJ, Hall A. Psychosocial and sexual impact of diagnosis and treatment of breast cancer. *Br Med Bull*. 1991;47:388-399.
6. McCaffery KJ, Jansen J. Pre-operative MRI for women with newly diagnosed breast cancer: perspectives on clinician and patient decision-making when evidence is uncertain. *Breast*. 2010;19:10-12.
7. National Comprehensive Cancer Network. *Clinical Practice Guidelines in Oncology: Breast Cancer*. V.2.2010. www.nccn.org/professionals/physician_gls/PDF/breast.pdf. Accessed March 15, 2010.

have someone who has a lot of inpatient and outpatient experience, you don't need that special credentialing. In the real world, however, where there are lots of job applicants, it's safer to get the credentials. Many people already have credentials offered by the Oncology Nursing Certification Corporation and the AOSW, so I'm not sure that any additional credentials are necessary.

What I do think is needed are educational programs for people who are seeking more specialized training. If new navigators do not have oncology nurse practitioners or oncology social workers available to help them, linkage to an organization that could help them learn some of the skills necessary for patient navigation would be very helpful.

DA: Kathy Allen and I are both

board-certified oncology social workers and are required to get a certain number of credits each year in psychosocial care or end-of-life issues. We both attend our national conferences and also participate in an online program where we can communicate with other professionals across the country on a daily basis.

Do you find that there are different

psychosocial issues associated with different types of cancers and is there a need for a designated navigator for different types of cancer?

DA: That has been our experience, and it's one of the reasons Diane branched off into head and neck cancer when we hired a breast navigator. That population has so many special needs. Kathy and I tend to see anybody under treatment for brain cancer because of that population's special needs in terms of ambulation problems, cognitive problems, and memory problems. Another population with special needs is patients who are having concurrent treatments in the chemotherapy and radiation offices, who often need a navigator help coordinate their care.

DM: Patients with preexisting mental health issues, such as those with depression or schizophrenia, are another population for whom a team approach is especially important. We rely on the social workers and outside mental health practitioners to keep those patients in treatment and on schedule.

Do you offer services for survivors after they've completed their treatment?

DA: Yes. We have several support groups up and running now because of voiced patient needs. Patients come to these groups for new information, to talk to other patients, and to get referrals. We also have special events during the year, including an annual survivor day that has grown so large we now hold it in a ball stadium.

What are some of the greatest challenges navigators are facing?

DM: One of the biggest challenges we are facing right now are the average working class patients whose treatment is demanding and are not able to work their full hours. They are financially at a disadvantage, and they may have to make serious choices about whether to get their prescriptions filled because they have lost half their income. They are not eligible for public assistance because they make a little too much money, and they are not eligible for Social Security disability benefits because they may go back to work within the next year. We have patients who have lost their insurance and are facing losing everything they have in the bank to pay for their healthcare.

The other limit for us is time. We work long hours, and even though we love what we do, we have to make personal decisions about working long hours to help our patients. Time management is a very important issue for us. ●

The Journal of Oncology

NAVIGATION & SURVIVORSHIP™

The Official Journal of the Academy of Oncology Nurse Navigators®

Author Guidelines

Manuscripts submitted to *The Journal of Oncology Navigation & Survivorship* (JONS) must be original and must not have been published previously, either in print or in electronic form. Manuscripts cannot be submitted elsewhere while under consideration by JONS.

To be considered for publication, manuscripts must adhere to the format described in this document. All manuscripts are subject to peer review, and acceptance is based on that review. If accepted, authors will be notified of any recommended revisions, and a revised manuscript should be resubmitted in its entirety, with all changes made.

Routine editorial changes will be made to conform to house style, following the *AMA Manual of Style*, 10th ed. (New York, NY: Oxford University Press; 2007). The edited manuscript is sent to the author for a final review and approval. Time from submission to publication is generally 3 to 5 months.

COPYRIGHT/DISCLOSURE

Authors are required to sign a Copyright Transfer Form, assigning all copyrights to Green Hill Healthcare Communications, LLC, publisher of JONS, as well as a Financial Disclosure Form. Authors are required to disclose any financial interests—direct or indirect—and any affiliations or involvement (competitive or amiable) with organizations that have a financial interest in the subject matter or materials discussed in the manuscript.

PERMISSIONS

Authors must secure written permission to reuse or adapt any table or figure from a previously published (online or in print) article or from any source. Provide the letter of permission when submitting the manuscript, or indicate that permission will be provided, and cite the original source with the graphic element in the manuscript.

MANUSCRIPT FORMAT

Title page: Include a proper title for the article and list the names, titles, and affiliations of all authors. Also list the name, address, telephone number, and e-mail address of the corresponding author.

Abstract: Provide a 150- to 250-word abstract that describes the main objectives of the article and why this article is important or what it adds to the literature.

Conclusion: The conclusion should add comments that offer the rationale for the article and what the article adds to the literature.

Double space the entire manuscript and number pages consecutively.

Tables and figures must be cited in the text, but the actual graphics must then be placed at the end of the article.

Length: 2500-3000 words, plus tables and figures.

Images must be saved as individual files, at high resolution (300 dpi), as jpg. Attach an individual file for each image. A copy may be included in the article but cannot substitute for an electronic image file. Images not saved appropriately will delay the peer-review process significantly. For help with images, please contact editorial@greenhillhc.com.

AUTHORS

Provide all authors' highest academic degree and all professional affiliations. Also provide the name, address, telephone number, e-mail, and fax of the corresponding author. If possible, please provide a headshot of the lead author.

REFERENCES

Cite references consecutively in the text (as superscript numbers), then place each complete reference at the end of the article under heading "References." Use proper citation format according to the *AMA Manual of Style*. See examples below. Use the most up-to-date, post-1990 references, citing primary sources only. Try to limit the number of references to about 30. **Do not use automatic numbering or footnote/endnote features.**

Reference examples:

1. Peters JL, Sutton AJ, Jones DR, et al. Comparison of two methods to detect publication bias in meta-analysis. *JAMA*. 2006;295:676-680.
2. McGrath JJ, Murray RM. Risk factors for schizophrenia: from conception to birth. In: Hirsch SR, Weinberger DR, eds. *Schizophrenia*. Oxford, England: Blackwell Press; 2003.
3. Waters R, Pettypiece S. Drug sales in the US grow at slower pace as generic use surges. Bloomberg news, March 12, 2008. www.bloomberg.com/apps/news?pid=newsarchive&sid=aLfUw7_sYMRy. Accessed March 13, 2008.

HOW TO SUBMIT MANUSCRIPTS

Save the entire manuscript as a Word file and attach individual files for each image. Save images individually as an image file (jpg). Digital graphics must be saved at a high resolution of at least 300 dpi. **Submit the manuscript to editorial@greenhillhc.com**. For assistance with the submission, call 732-992-1890.

REPRINTS

Reprints may be ordered at a nominal fee by contacting editorial@greenhillhc.com.