

Bringing National Breast Cancer Research and Practice Trends to the BCDP

The Breast Cancer Demonstration Project (BCDP) held its fourth Advisory Board meeting on November 4 at Lutheran Medical Center in Brooklyn. At the meeting, the Advisory Board reviewed news and information from two recent national breast cancer events: The 1999 Comprehensive Cancer Control Conference of the federal Centers for Disease Control and Prevention and Johns Hopkins' 1999 Seeking Excellence in Breast Cancer Care Conference. The Advisory Board also discussed the year 2015 cancer goals of the Centers for Disease Control and Prevention and American Cancer Society and implications for cancer services leadership. National cancer management and practice trends were highlighted and related to the work of the BCDP.

Highlighted trends include:

- ◆ *integrating services throughout the continuum of care;*
- ◆ *leadership convening multi-disciplinary treatment teams;*
- ◆ *increasing use of case management and ambulatory care;*
- ◆ *increasing attention to patient diversity;*
- ◆ *transforming health practice to view breast cancer as a chronic disease, emphasizing early screening and detection;*
- ◆ *using treatments that optimize local control of the disease;*
- ◆ *moving from research and treatment in medical centers to prevention and control in communities; and*
- ◆ *partnerships with private and public organizations, leading to better and more comprehensive services.*

Another national focus has been increased attention to quality assessment at all stages of breast health care. The BCDP invited Lillie Shockney, Director of Outreach and Education at the Johns Hopkins Breast Center, to its Advisory Board meeting. Ms. Shockney discussed the purposes and strategies of quality

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assessment and performance improvement in breast cancer care. Her presentation described specific examples of performance improvement initiatives that will meet Joint Commission on Accreditation of Health Care Organizations (JCAHO) standards.

The Advisory Board also discussed a number of practical topics in working groups. Topics included review and use of free patient education materials, assessing patient satisfaction, and standards for mammography utilization and reimbursement.

The next meeting of the Advisory Board is scheduled for February 16, 2000.

Innovative Approaches to Patient Care Highlights of Lillie Shockney's Presentation On Performance Improvement and Measurement At the BCDP Advisory Board Meeting November 4, 1999

- Ms. Shockney defined the best quality of treatment as doing what is efficacious for the condition and appropriately treating the patient's needs.
- Prior to any surgical intervention, Johns Hopkins' Breast Center staff spend a half day with the new patient, providing information, planning treatment, and developing goals and expectations for treatment. Patients are given a standard set of materials to take with them. Johns Hopkins finds that this level of education and counseling greatly reduces post-surgical morbidity.
- Encouraging patients to participate in treatment decisions allows patients to be empowered about their treatment and to feel in control of the process.
- Incorporating survivors' experiences has helped to enlighten the development and refinement of services.
- The Johns Hopkins Breast Center uses a Patient's Bill of Rights to help the patient understand what he or she can expect throughout the course of treatment.
- The Johns Hopkins Breast Center also makes a point of publicly displaying its treatment performance. Key indicators are measured and reported to patients and the public; all staff are encouraged to achieve and maintain excellence.
- For Ms. Shockney, a major component of healing is hope. She and the other staff strive to give consistently positive messages that promote wellness and a sense of control for the patient.

For more on the Johns Hopkins approach to Breast Cancer Services, visit their Web page at <http://www.med.jhu.edu/breastcenter>.

Breast Health Navigator Resources and Tools

A variety of resources and tools are available to help breast health navigators when assisting breast cancer patients. Below are some examples.

Resource Guides

A Helping Hand: The Resource Guide for People with Cancer.

Cancer Care, Inc. 275 Seventh Avenue, New York, NY 10001
It is available free in bound version by calling (800) 813-4673 or on-line at www.cancercare.org/hhrd/hhrd.htm.

The Helping Hand Resource Guide is a nationwide directory of free services and resources for people with cancer. The guide is designed for health care professionals and for cancer patients and their families. The guide has listings of national, regional, state, and local organizations, and national cancer centers, retailers, and other groups and agencies that help people with cancer.

The Helping Hand Resource Guide contains information about services including advocacy, financial assistance, home care, hospice care, housing and lodging, medication manufacturers' indigent drug programs, minority health services, patient-to-patient support, state pharmaceutical assistance programs, survivor concerns, and transportation services. All listings are indexed alphabetically, by service, cancer site, e-mail, and "800" number. Whether you are looking for general information on cancer, or specific services, this guide is designed to answer your questions or direct you to someone who can.

Case Management Resource Guide, Volume 1: Eastern U.S.

Center for Healthcare Information, PO Box 16067, Irvine, CA 92623.
Available in bound version for \$49 by calling (800) 627-2244, or free on-line at www.cmrg.com/guide.htm.

The Case Management Resource Guide lists health organizations, self-help groups, government agencies, and clearinghouses that provide information or support resources for patients and their families. It is designed for use by case managers, discharge planners, and social workers, among others. Cancer management resources include: disease management programs and vendors, information and support resources, manufacturers of home care and assistive technology products, and relevant Web sites.

Topics include diseases, health conditions, and health issues. Health-related state agencies that are listed provide information or financial support, and can refer you to other local services. Many of the national organizations listed can also refer you to their local chapters.



What's Helpful on the Web?

Case Management Related Journals Lippincott's NursingCenter.com

Available free on-line at www.nursingcenter.com/journals.

NursingCenter.com has a page of links to online journals that may be helpful when researching and developing case management programs. Many articles from the journals can be read on-line and printed free; others are available for a modest fee. Full-text journal articles are fully searchable and issues are available from January 1996 forward. Journals listed include: [Nursing Case Management, Outcomes Management for Nursing Practice, Cancer Nursing, Nursing Research, Computers in Nursing, and more].

The Cancer Survival Tool-Box™ National Coalition for Cancer Survivorship (NCCS) 1010 Wayne Avenue, Suite 505, Silver Spring, MD 20910-5600

Available free on-line at

www.cansearch.org/programs/toolbox.htm.

Available free in audio cassettes with booklet by calling (877) 866-5748.

The Cancer Survival Tool-Box™, a self-learning audio program, is designed to help individuals with cancer learn about practical topics and skills that can help them meet the challenges of their cancer diagnosis and treatment. The toolbox includes six self-learning audio programs: communicating, finding information, making decisions, solving problems, negotiating, and standing up for your rights. A new tape, "Finding Ways To Pay for Care," has been added to the box, and is designed to address the specific issues faced by individuals who have either inadequate or no health insurance.

The program is designed to assist anyone, at any stage of illness, who is facing hard decisions and changes in life because of cancer. Family members and caregivers can also use the toolbox on behalf of a child or anyone else with cancer. Survivors, social workers, and nurses, representing a unique collaboration of the National Coalition for Cancer Survivorship, the Association of Oncology Social Work, and the Oncology Nursing Society designed the Cancer Survival Tool-Box™.

MEDLINEplus Health Information Breast Cancer Page National Library of Medicine at the National Institutes of Health

Available free on-line at www.nlm.nih.gov/medlineplus/breast-cancer.html.

Available in English and Spanish

MEDLINEplus, a Web-based program designed to help consumers easily access health information on the Internet, has been implemented by the National Library of Medicine at the National Institutes of Health (NIH). The MEDLINEplus' breast cancer page is intended for both consumers and health professionals with medical questions about breast cancer. This service provides access to extensive information about breast cancer, and also has links to consumer health information from NIH, clearinghouses, dictionaries, lists of hospitals and physicians, health information in Spanish and other languages, and clinical trials.

Regulatory Corner

HCFA Accepting Comments on New Breast Imaging Policy

On October 29, the federal Health Care Financing Administration (HCFA) released a draft policy on "Breast Imaging: Mammography/Breast/Echography (Sonography) Breast MRI/ Ductography" for Medicare Part A. The draft policy was presented by Empire Medicare Services as the fiscal intermediary for HCFA.

The draft policy makes clear distinctions between screening and diagnostic mammography, and indicates what is required, allowed, and billable for each procedure. Among other distinctions, the policy indicates that payment for screening mammography is not allowed for women under age 35, and that up to age 40, only one baseline mammogram will be reimbursed. In addition, while the Part B deductible is waived for screening mammograms, the deductible will be charged for diagnostic mammography. Other provisions include procedures for notifying patients when there is no referring physician, and the use of other radiology procedures when mammography cannot definitively identify breast abnormalities.

HCFA invited comments until December 15, and HANYS coordinated a response to the draft policy. For more information on the policy and HANYS' response, please contact Virginia Homsy, BCDP Program Director, at (518) 431-7754, or vhomsy@hanys.org.

Patient Navigation and Case Management in Breast Cancer Services

In providing breast cancer treatment, hospitals frequently use specialized staff to help patients navigate various treatment services. Sometimes called “case managers” or “patient navigators,” these individuals are information resources, points of contact, and record keepers. In a recent article in *Nursing Case Management*, Patricia Taylor, RNC, MS, states that case management programs for breast cancer patients will “foster informed participation in treatment decision making, relieve anxiety, and restore some sense of control to (patients’) lives.” Ms. Taylor also notes that “most women are willing to participate actively in their own care but are given insufficient information to do so.” Navigators help to clarify choices and bridge gaps to care.

To learn more about this interesting role, the BCDP staff spoke with members of the Advisory Board. Connie Baird is the Coordinator of Breast Health Services for the North Shore-Long Island Jewish Health System. Brenda Blane is the Administrator of the Cancer Control Clinic of Harlem Hospital Center. Judy Koles is the Nurse Coordinator of the Breast Care Center at Huntington Hospital.

Here’s what they had to say:

What is the role of the patient navigator?

Connie Baird (CB): The patient navigator ensures follow-up of patients with abnormal clinical breast exams or mammography findings and assists patients to overcome barriers before they become an obstacle to timely diagnosis and treatment and follow-up care. This is done on a one-to-one basis by linking women to services available in the community.

Brenda Blane (BB): The patient navigator is a social advocate who clears and/or facilitates the challenges and barriers that impede a patient from receiving quality medical services and treatment in the hospital setting, as well as barriers to the medical services caused by challenges of a social nature.

Judy Koles (JK): The patient navigator sees, from the time of suspicion of cancer, that each person is equally and adequately afforded prompt care that is the standard of care at the time. The navigator prevents “lost to follow-up” and removes barriers to quality care for each individual.

Is there a difference between patient navigation and case management?

JK: I think case management is much more broad and non-specific. A case manager may be somewhat retrospective and a navigator, prospective.

CB: Unlike a social worker, the patient navigator is a sort of “social servant.” The navigator concentrates on the concrete needs of patients with abnormal findings related to cancer and focuses on ensuring prompt follow-up for all cancer-related symptoms.

BB: Patient navigation is a type of case management and works congruently with the social worker, medical providers, financial clearance, and community social services to deliver

treatment and follow-up services from the point of abnormal findings to follow-up. The patient navigator offers very individual case management.

What is the job description for a patient navigator?

BB: A patient navigator serves as a liaison between a medical center and community with the responsibility for coordinating and implementing cancer education to reach targeted audiences. The navigator facilitates liaison activities to encourage intermediary involvement with the center, and maintains those relationships on an ongoing basis. Additional responsibilities include: participation in health fairs, educational seminars, etc., to establish contacts and presence within the community; contacting all patients with abnormal findings from cancer screening to ensure timely appointments; walking patients through pre-admission testing; providing education materials for patients; contacting patients to reschedule missed appointments; assisting physicians in retrieving clinical records; and contacting appropriate support systems for patients after completion of treatment.

JK: The patient advocate/friend will guide and facilitate a person through the terror of cancer diagnosis and treatment. He or she will explain medical terms and help with insurance, transportation, and family issues, both physically and emotionally.

CB: In Suffolk County, the position is funded through the Suffolk County Department of Health Services and requires a registered nurse who will support the patient as he or she journeys through the path of abnormal findings to surgery after care and treatment. In addition to the functions listed above, the patient navigator may arrange for transportation, childcare, interpretation, and support services. The navigator also may accompany patients to follow-up appointments and assist with health insurance issues.

What are the qualifications that a patient navigator should have?

JK: Navigators need good communication skills, patience, and a complete knowledge of the start-to-finish patient experience at their institution. The person should be persistent and thorough. He or she also needs to be proactive and access things for the patient that the patient otherwise might not have received.

BB: The navigator needs excellent oral and written communication skills, interpersonal skills, organizational skills, listening and observation skills, a sense of humor, flexibility, the ability to work with all socio-economic levels, persistence, determination, initiative, and patience. The person should be a creative problem solver and have a good knowledge of community resources.

CB: In addition to one-to-one counseling skills, the navigator needs to be comfortable speaking in public to educate providers and patients about navigation services and have an ability to advocate for patient needs while accessing community resources.

When does the navigator become involved with a case, and how long does the navigator work with the patient?

BB: Navigation begins from the point of a suspected abnormality to rehabilitation services when an abnormality is found.

JK: Navigation begins from the time of initial abnormal findings on a mammogram or clinical exam through adjuvant treatment.

Are there other functions for the patient navigator, such as policy development, quality assurance, and performance assessment?

BB: Yes. Periodic meetings are held to review and develop policy, and review, develop and maintain quality assurance and performance assessment. These tasks are completed with overall hospital staff and as a unit.

CB: In Suffolk County, the patient navigator position is funded through the Suffolk County Department of Health Services. The navigator tracks patients with a computer system, enters the data and creates tracking reports for the Department of Health.

JK: All of the above.

How can the patient navigator help to improve clinical outcomes?

CB: The navigator helps to decrease the disparity in services and treatment that under-served populations face. Specific outcomes include increased utilization of services, increased access to health insurance, decreased disruption of the patient's personal and working lives, decreased pain and suffering, decreased fatalism about cancer and enhanced quality of life.

JK: Through documentation, clear goals, and follow up. Again, nothing is lost between the cracks.

BB: The main jobs of the navigator are to follow up with patients and provide education. Examples of ways that navigators help outcomes include rescheduling of missed appointments, resolution to barriers, interpretation of terminology into lay-person's terms, patient education regarding disease, encouragement when patient is fearful, and reminders of annual screenings. Document retrieval is another task that the navigator performs to facilitate timely and appropriate treatment.

As our approaches to breast cancer treatment have evolved, how has the role of the patient navigator changed?

JK: We're defining more options. As standards for procedures such as core biopsy and sentinel node dissection have been developed, we have more that we can offer. Our jobs are to make patients aware of choices.

BB: We can do more outreach now because patients are more receptive to talking about breast cancer. Also, we have more collaboration with other communities' social and medical networks. We have greater patient loads because the stigma of cancer has been reduced, and patients want to know more about the

disease. We have greater involvement with support groups that use volunteers to help patients, and all of us have developed a continual upgrade in knowledge of the disease.

What are the first steps to implementing a patient navigation/case management program?

BB: First, conduct a community needs assessment to identify barriers and resources. Then, do what you can to build systems and networks to resolve barriers, and to provide high quality and timely services, including outreach, recruitment, and education. Put a high emphasis on the dignity and worth of the patient, and be consistent in follow-up and resolution of barriers.

CB: The navigator needs to be a community member who has a history of working with local groups, collaborations and advocacy outreach programs. He or she should be able to publicize the program to make sure physicians know how to get in contact with him or her.

JK: Funding is also important. You need to commit resources to allow the program to develop.

Do you have any advice for medical staff who begin working with patient navigators?

BB: Listen to and observe rapport with patients. Keep navigation staff aware of what you do and why. Utilize navigators to reinforce your medical advice. Ask for ideas on how to be more successful. Emphasize the role of the navigator in clearing barriers to medical improvement services. Openly thank navigators for making your and the patient's journey more successful. Provide opportunities for discussion and continuous education about the disease.

JK: Be patient and understanding of the immediacy of navigator's needs. Give the program a chance and see that working with navigators will help patient care.

What results can the patient expect from using a navigator?

JK: I see three themes: more efficient care, attention that is both individualized and guided, and the feeling that the patient and his or her health is important.

CB: The patient can expect that the burden of being diagnosed with cancer can be shared. Navigators can give information to educate patients about resources and options for care which can reduce anxiety and provide a more optimistic outlook. Patients are encouraged to ask questions because there will always be someone there to listen and assist in finding answers, and accessing care.

BB: There are a number of results for patients: one-on-one education, support from a health care provider, resolution to unforeseen and challenging barriers, reminders to solicit good health care, encouragement to sustain overall good health care, a positive entity to encourage good health, and a problem-solver who will assist you in "learning to fish."

¹ **Case Management Program for Breast Cancer Education.** (1999). *Nursing Case Management*, 4 (3), 135-144.



News

FROM THE BCDP SITES

The Breast Cancer Demonstration Project welcomes two new sites to the Project: **North General Hospital in Harlem** and **Sound Shore Medical Center of Westchester.**

F.F. Thompson Hospital has begun construction of its new cancer center, which is a collaborative project of Thompson Health and Strong Memorial Hospital. In addition to traditional diagnosis and treatment, the center will include integrative and complimentary therapies. The center is scheduled to open in the spring of 2000.

North General Hospital has hired a nurse to begin the patient navigation program for that hospital. In addition, North General is beginning work on a palliative care service and expanding the in-patient space for cancer patients.

The North Shore-Long Island Jewish Health System (NSLIJ) has hired a breast services coordinator to act as a clearinghouse of breast cancer service information for the 13 hospitals in the NSLIJ system. The coordinator will gather information on all of the breast health services offered in the system's hospitals, and then make those services known throughout the system.

The coordinator is also researching ways to increase collaboration among hospitals.

St. John's Riverside Hospital has developed a satellite women's health center in an urban part of Yonkers. The satellite center provides health information and services to an under-served part of their community, and makes referrals for breast screening. This outreach effort has drawn more patients to the St. John's breast center, and given many patients the opportunity to use their new resource library. St. John's is also partnering with the home health company Home Care America to raise community awareness of its breast center and library.

In October, **Sound Shore Medical Center** opened its new breast center. The center intends to coordinate quality care by using a team of medical professionals to treat patients. Included in the center is a patient education and counseling area, mammography, ultrasound, and stereotactic biopsy suites, as well as offices for radiologists and surgeons. Support services are also available through the breast center.

Coming Soon! The Breast Cancer Demonstration Project Web site.



Look for this site as part of the HANYS' Web page in a few weeks. Information will include: background on the project, project partners, goals, objectives and deliverables, and links to other breast cancer information on the Internet. HANYS' Web page is at: www.hanys.org.

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