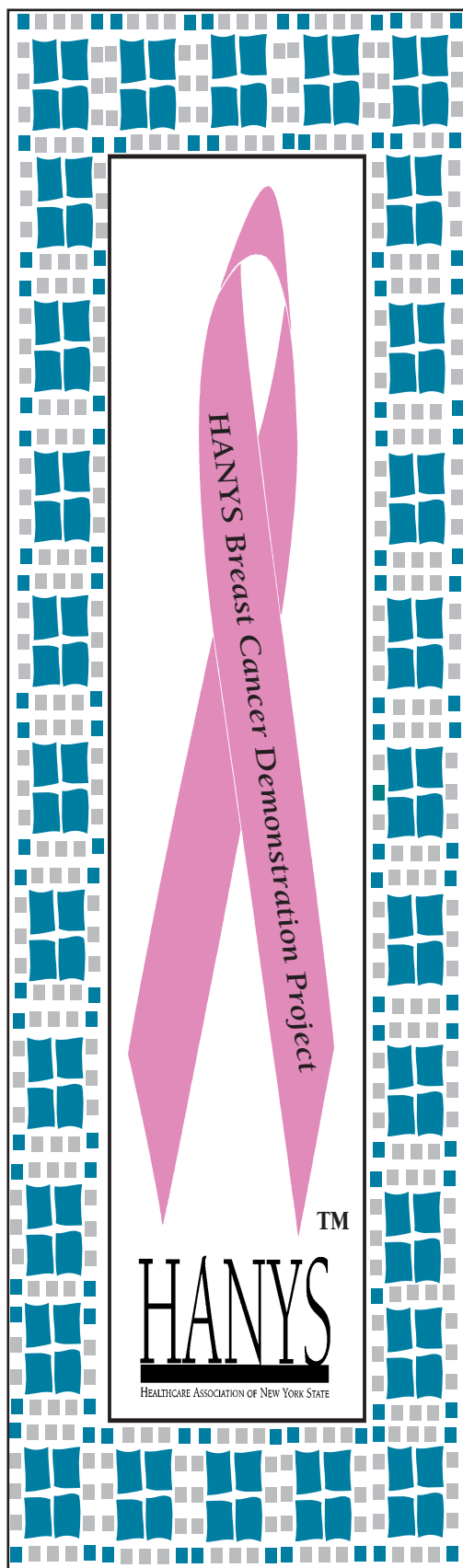


March 2003



PATIENT AUTONOMY: Responding to Patient Needs in Breast Cancer Care/ Provider-Patient Tools for Decision Support

The cornerstone of patient autonomy is acknowledging and honoring each patient's right to be treated with dignity, care, and respect and providing an opportunity to hear the patient's views regarding care and treatment decisions. As patients and families take an increasingly participatory role in care and require a greater level of communication with their physicians and health care providers, the opportunities for collaboration between patients and physicians expand, as do the implications for clinical practice.

Recently reported results of breast cancer patient focus groups¹ highlight the benefits of collaboration, including greater levels of understanding of the disease, less psychological distress, and higher levels of satisfaction with health care providers. The American Academy of Orthopaedic Surgeons recently reported, "Effective communication is associated with improved patient and physician satisfaction, better patient compliance, improved health outcomes, better informed medical decisions and reduced malpractice suits, and it likely contributes to reduced costs of care."² The Academy is working to revise physician education curricula and to assist in the design of national certifying exams on physician-patient communication. Moreover, new guidelines for physician-patient communication, consisting of various training modules, are being required within the curricula at medical schools.³

Breast cancer patients and family members struggle as they to come to grips with the breast cancer diagnosis, treatment, side effects, and prognosis. They are often ill equipped to effectively communicate and process medical jargon into an understandable framework and express their needs during the doctor visit. The result is too often a frustrated, angry patient whose impression of the medical encounter may result in not "hearing" the news, and not "getting" the message. The medical/legal perspective on risk management, threat to professional liability, and the need for good physician/patient communication has been written about extensively in the publication, Same-Day Surgery.⁴

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¹ *Cancer Nursing*, Vol. 24 No.3, 2001.

² *Journal of the American Academy of Orthopaedic Surgeons*, March-April 2002, 10 (2), pp. 95 - 105.

³ Lefevre, Frank, V.; Waters, Teresa M.; Budetti, Peter P. "A Survey of Physician Training Programs in Risk Management and Communication Skills for Malpractice Prevention" *Journal of Law, Medicine & Ethics*, Fall 2000, Vol. 28 Issue 3.

⁴ *Same Day Surgery* Sept. 2001 Vol. 25 Issue 9, p. 102

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Overcoming Barriers to Communication through the HANYS BCDP™ Resource Kit

Women are often emotionally overwhelmed after they receive a diagnosis of breast cancer. During this time of emotional upheaval, many crucial decisions must be made regarding their treatment and follow-up care, which will have a long-term impact on their quality of life and ability to return to their activities of daily living.¹ During the critical period after the initial diagnosis of breast cancer, both health care providers and newly diagnosed women may experience significant communication challenges.

In response to a patient and health care provider needs survey, HANYS BCDP™ and its Advisory Board members developed *Provider Tools for Bridging the Gap: A Resource Kit for Helping Newly Diagnosed Breast Cancer Patients*. This Resource Kit addresses communication issues and the obstacles to care that may arise during this critical period, from both the health care provider and the patient perspective.

Based on a review of the literature and input from the Advisory Board workgroup, critical elements that may affect the development of a collaborative physician-patient relationship at the time of diagnosis were identified and grouped under four challenge areas addressed in the Resource Kit:

- Sharing the Diagnosis
- Fostering Patient Autonomy
- Guiding and Providing
- Overcoming Cultural Obstacles

Health care providers can offer critical assistance to women confronted with a breast cancer diagnosis in the period between hearing their diagnosis and getting through their course of treatment. This relationship begins with sharing the diagnosis.

Physicians must address complex informational needs of newly diagnosed women to educate them about their disease and pre-

pare them for crucial decisions. For breast surgeons and medical oncologists, these will most likely be new patients who were referred to them following suspicious mammography findings. Lacking an established relationship and knowledge of patients' coping mechanisms and support systems, these doctors must carry out the stressful task of breaking the bad news of a cancer diagnosis, while trying to discern a patient's preference for receiving detailed information about the diagnosis and prognosis, along with a patient's comfort level for active participation in shared decision-making.

To complicate matters, the patient's emotional response after hearing the news may be difficult for physicians to deal with and may render the patient temporarily unable to understand the critical information that the physician is trying to communicate. These are not easy tasks for physicians to accomplish while struggling with the time pressures of a busy clinical practice.² Arranging psychological and social support often must precede the decision-making phase to allow the patient time to absorb the shock of diagnosis and prepare for the road ahead.

Health care providers caring for diverse populations may face additional difficulties at time of diagnosis, such as language barriers and cultural beliefs and attitudes that can affect patients' understanding of diagnosis, subsequent treatment, and follow-up care for breast cancer.

Researchers suggest that health care providers and patients can benefit from effective communication practices that support patients' initial psychological adjustment.^{3,4} This strategy sets the stage for establishing collaborative relationships that can enable patients to participate in shared decision-making and gain a sense of control over their illness.

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How the Resource Kit can help:

The *Resource Kit* includes strategies, tips, resources, and tools to help both health care providers and patients overcome the multiple challenges that can arise once a diagnosis of breast cancer is made. The kit has been designed specifically to:

- help health care providers break the bad news of diagnosis and help patients cope with hearing the news;
- encourage providers to establish an environment for supporting initial adjustment and increasing patient's access to early emotional and psychosocial support;

- enhance health care providers' and patients' ability to work collaboratively toward shared decision-making and help patients become informed partners in their care;
- support health care providers in guiding patients to reliable information and providing access to follow-up support; and
- link health care providers with resources to help culturally diverse patients overcome barriers to quality care.

One researcher sums up the connection between communication and patient satisfaction this way: "How the process of information sharing and relationship building unfolds ultimately contributes to, or detracts from, the woman's experience of control over her own life and health, and to her learning to live with cancer."¹

¹McWilliam, C. Brown, J, Stewart, M., "Breast cancer patients' experiences of patient-doctor communication: a working relationship." *Patient Education and Counseling*, 2000, (39) p. 201.

For more information on the *Resource Kit*, contact HANYS BCDP™ at (518) 431-7661.



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The goals of the HANYS BCDP™ *Provider Tools for Bridging the Gap Resource Kit* are:

- to link providers and patients with identified resources to help reduce the barriers and obstacles in communication experienced by both providers and patients following a diagnosis of breast cancer; and
- to reinforce the collaborative partnership between physicians and patients and facilitate informed choices and decision-making.

These goals may be achieved through the timely implementation of evidence-based strategies that can enhance effective communication and foster satisfactory collaborative relationships for meeting individual's needs.

Potential benefits include:

- more efficient visits through improved information sharing;
- patients are better prepared for informed decision-making;
- improved health outcomes through improved understanding of and adherence to treatment plans;
- increased sense of control for the patient; and
- enhanced patient satisfaction.^{5,6}

While it may be most beneficial to implement evidence-based strategies for enhancing communication at the time of diagnosis, when early support is needed and decision-making is crucial,⁷ attention to communication skills that can enhance quality of care for patients at any stage of the continuum is appropriate. Women diagnosed with breast cancer have an ongoing need for effective communication to experience quality care throughout their continuum of treatment and personal journey toward recovery. Patients who become empowered through effective communication with physicians have reported experiencing a sense of control over their illness, a positive adjustment to the diagnosis of breast cancer, and long-term satisfaction with care.⁸

¹Sepucha, K., Belkora, J., Mutchnik, S., Esserman L, *Journal of Clinical Oncology*, 2002; (20) 2695-2700.

²VandeKieft, G. *American Family Physician*, December 15, 2001; (64) 12, 1975-1978.

³Mager, W. Andrykowski, M. *Psycho-Oncology*, 2002; (11) 35-46.

⁴Baile, W, Buckman, R, Lenzi, R, Glober, G, Beale, E, Kudelka, A. *Oncologist*, 2000; (5) 302-311.

⁵Baile, W. www.conversationsincare.com/web_book (Chapter 1) 2002.

⁶Bakker, D. Fitch, M., Gray, R., Reed, E. Bennett, J., *Patient Education and Counseling* 2001 (43) 61-71.

⁷Sepucha, K., Belkora, J, Tripathy, D., Esserman, L., *Journal of Clinical Oncology*, 2000; (18) 1230-1238.

⁸McWilliam, C., Brown, J., Stewart, M., *Patient Education and Counseling*, 2000; (39) 2-3:191-204.

Related Publications of Interest

How to Break Bad News: A Guide for Health Care Professionals

This book provides an in-depth discussion on the difficulties in delivering “bad news” to patients. The author, Robert Buckman, is a medical oncologist and a leading authority on this subject. He relates the importance of forming communication skills and lists the basic steps to a successful medical interview. A large portion of the book is dedicated to providing hints on responding to the reactions of patients, their family and friends, and other health care professionals. It also discusses ethical, cultural, and legal issues.

Buckman, R., *How to Break Bad News: A Guide for Health Care Professionals*, Baltimore, Johns Hopkins University Press, 1992.

Breaking Bad News

This article discusses the difficulties many physicians encounter when relaying end-of-life information to patients. It gives insight into ways to communicate bad news to patients in a caring and thoughtful manner. It also relays why physicians often feel ill equipped to communicate bad news to their patients. The author utilizes the mnemonic “ABCDE” as a tactic to assist with difficult end-of-life conversations. ABCDE stands for advance preparation, building a therapeutic relationship, communicating well, dealing with reaction, and encouraging/validating emotions.

Vadekief, *American Family Physician*, December 2001, 64

Is there Consensus Between Breast Cancer Patients and Providers on Guidelines for Breaking Bad News?

This article discusses a unique study that surveyed 84 breast cancer patients, 64 oncologists, and 140 oncology nurses. The survey asked the subjects to rate the importance of 15 general principles and 12 recommended steps to guide clinicians in communicating bad news to patients.

Girgis, A., Sanson-Fisher, R. W., Schofield, M., *Behavioral Medicine*, Summer 1999, (25): 69-77

Communication in the Cancer ‘Bad News’ Consultation: Patient Perceptions and Psychological Adjustments

This study concluded that women who have a positive view of a provider's behavior, regardless of satisfaction with that behavior; have a better long-term adjustment. The same was true if women feel providers were caring and supportive when breaking the bad news about their cancer. Women who rated their providers as caring were likely to also rate them as competent and understanding.

Mager, W.M.; Andrykowski, M.A.; *Psychooncology*, January 2002, 11(1): 35-46



What's New on the Web?

PHYSICIAN-PATIENT COMMUNICATION ENHANCEMENT WEB SITES

End of Life Physician Education Resource Center www.eperc.mcw.edu

The End of Life Physician Education Resource Center functions as a clearinghouse for educational materials, training materials, publications, and conferences that are specific to end-of-life issues. A main goal of this organization is to assist physician educators and others in locating high quality, peer-reviewed training materials.

Risk Management Foundation www.rmfm.org

The Risk Management Foundation (RMF) of Harvard Medical Institution is an evidence-based risk management services organization. Topics include patient safety, quality improvement, and claims management. RMF's Web site offers information related to its risk management services. Articles describing how communication skills affect risk management issues can be accessed by performing a search using the term "communication."

GENERAL BREAST CANCER INFORMATION WEB SITES

Cancer Links www.cancerlinks.org

This site's goal is to make searching for cancer information on the Web faster and easier. It offers links to sites that have information regarding various types of cancers; this includes general information, pain management, alternative medicine, and charitable air transportation for cancer survivors. This site also includes some international links.

Gillette's Women's Cancer Connection www.gillettecancerconnect.org

This site provides information related to cancer survivors' shared experiences; guidance and support for women, friends, and family; tools and resources; and communication guides for helping people with cancer to communicate with their partners, children, parents, friends, doctors, and co-workers. This site also presents articles that offer insight into challenging topics (i.e., how to talk to children about a parent's cancer diagnosis, getting the most out of patient-provider relationships, and feature articles written at age appropriate levels for children).

Adelphi NY Statewide Breast Cancer Hotline and Support Program www.adelphi.edu/nysbreastcancer

This Adelphi University site has information regarding Adelphi's statewide toll-free Breast Cancer Hotline at (800) 877-8077.

Information is available about free written materials from many sources including the National Cancer Institute and the American Cancer Society, as well as Adelphi's own material.

CULTURE-SPECIFIC WEB SITES

Breast Health Access for Women with Disabilities www.bhawd.org

This site highlights a community partnership that is tailored to women with disabilities and health care providers who work with this patient population. The site provides detailed information and pointers on how women with disabilities can work with health care providers to get the care they need. There is also a demonstration for women with special needs on how to properly perform breast self-examinations. The site offers a guide for practitioners who perform breast and gynecological examinations on women with disabilities. Titled *Table Manners and Beyond*, this guide provides direction for preparing the patient for a successful examination, communicating with the patient, and alternative positioning and transferring.

Ethnomed <http://ethnomed.org>

The University of Washington Harborview Medical Center offers a Web site that contains culture-specific information regarding cultural beliefs and medical care. Specific information is available regarding the Cambodian, Chinese, Somali, and Vietnamese cultures.

University of Washington Medical Center <http://depts.washington.edu/pfes/cultureclues.html>

The University of Washington's Patient and Family Education Services Department offers Cultural Clues™© — tip sheets to help health care professionals gain insight and understanding into patients' preferences, specific to Albanian, African-American, Chinese, Korean, Latino, Russian, and Vietnamese cultures. Each tip sheet discusses how specific cultures deal with illness, how medical decisions are made, managing medical news, understanding relationships, improving communications, and cultural norms.

The American Medical Association www.ama-assn.org/ama/pub/category/2661.html

The American Medical Association cultural competence compendium is a collection of resources for physicians and the public.

National Cancer Institute www.cancer.gov

The National Cancer Institute has created a new publication for Latino cancer survivors, their families and friends, and health care professionals. *Siga Adelante: La Vida Después Del Tratamiento Del Cáncer* is an adaptation of *Life After Cancer Treatment*. This resource offers scientific information from health professionals and coping tips from cancer survivors to help them face the challenges of life after treatment. This book is now available at www.cancer.gov/espanol/vida-despues-del-tratamiento. To order free copies call (800) 422-6237.



News

FROM HANYS BCDP™ SITES

Funding from the New York State Assembly Majority and the federal Centers for Disease Control and Prevention (CDC) Division of Cancer Prevention and Control supports HANYS BCDP™ participating hospitals' projects that help health care providers deliver exemplary care, enhance the quality of life for breast cancer patients, and decrease barriers to care and increase access for patients.

Arnot Ogden Medical Center

Arnot Ogden Medical Center in Elmira continues to screen breast health patients through its Health Center for Women and its satellite breast imaging facility, where about 220 patients receive screening mammograms each quarter.

The Health Center for Women recently held a “Women’s Health Day.” Forty women received breast health information and education on the importance of early detection, breast self-examination, and mammography.

Benedictine Hospital

Benedictine Hospital in Kingston continues its breast cancer outreach efforts, including targeting special populations utilizing traditional and non-traditional strategies. Benedictine’s breast health navigators provide educational programs at senior citizens’ clubs, health fairs, churches, Healthy Start Family Services in Kingston, the Ulster Community Corrections Department, and through the Benedictine Hospital Oncology Support Program.

Twenty-six women received a mammogram and a clinical breast examination at Benedictine’s recent “Walk-In Mammography Day.” A representative from the local Healthy Women Partnership Program was on hand to enroll eligible women in the program immediately.

Crouse Hospital

Crouse Hospital in Syracuse successfully completed its In-House Mammography Program, which encouraged female employees, 40 years of age and older, to get screening mammograms.

Crouse has formed an Out-Reach Advisory Committee that is developing and implementing a strategic plan to provide breast cancer awareness to underserved communities in the Syracuse area.

Long Island College Hospital

Long Island College Hospital in Brooklyn hosted a series of Hormone Replacement Therapy (HRT) lectures attended by health care professionals and the public. The purpose of the series was to provide information specific to HRT, refute media myths, discuss the pros and cons of HRT, and encourage the audience to ask questions.

The hospital recently held a “Spa Day” that offered nutritional education and complementary therapies (i.e., aromatherapy, flower essences, meditation, yoga, polarity, Reiki therapy, Swedish massage, and Tai Chi).

Lutheran Medical Center

Lutheran Medical Center in Brooklyn recently opened the Brooklyn Chinese Family Health Center, which provides bilingual health care providers and support staff. To allow for flexible scheduling, the Center is open on Sundays. In addition, Lutheran opened the Bay Ridge Family Health Center, staffed with bilingual health care providers to serve the large community of Russian and Arabic speaking patients. Both sites provide obstetric and gynecological services.

New York Community Hospital

New York Community Hospital in Brooklyn, which serves a large Russian immigrant population, has hired a bilingual patient navigator to continue guiding breast cancer patients through the health care system and assist with access to appropriate resources and services.

New York Hospital Queens

New York Hospital Queens in Flushing is initiating an Employee Mammography Inreach Program, which encourages female employees over the age of 40 to get annual mammograms, educates women regarding screening guidelines, and increases their awareness of breast cancer.

New York Hospital Queens continues its outreach efforts by forming relationships and offering educational classes to churches, clubs, and organizations in the community. An annual event held in collaboration with the Eastern Division Chinese unit of the American Cancer Society offers free clinical breast examinations and education to Chinese women—this past year; 70 women had free clinical breast examinations through this event.

North General Hospital

North General Hospital in New York City continues its breast cancer outreach through its bilingual outreach team, with an emphasis on minority populations. The team participates in and hosts community health fairs, visits community organizations, and provides educational presentations and free clinical breast examinations.

In April, North General Hospital will transfer its existing outpatient oncology, hematology/oncology, and cancer screening services to a new facility, the Ralph Lauren Center for Cancer Care and Prevention. The Center’s focus is to provide patient care and support components, systems to ensure ease and access to services, and research to advance health outcomes for underserved minority populations.

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North Shore-Long Island Jewish Health System

North Shore-Long Island Jewish Health System in Great Neck is developing a standardized Breast Cancer Patient Resource Guide to help newly diagnosed breast cancer patients through the stages of breast cancer treatment; provide them with reliable information; and encourage communication with family members, doctors, and other health care providers to assist in informed decision making.

In 2000, the health system established a model for the Employee Mammography Inreach Project. Through this program, female employees receive breast cancer screening guidelines and women over age 40 are encouraged to schedule annual mammograms. A number of breast cancers have been identified among the system's employees through this project.

St. John's Riverside Hospital

St. John's Riverside Hospital in Yonkers continues to utilize the patient navigation process to ensure proper follow-up for patients with abnormal clinical breast examinations or mammograms. The navigator functions as a liaison between the patient and the physician, assisting the patient as she moves through breast cancer diagnosis, treatment, aftercare, and support. The navigator reached out to uninsured and underinsured women and local women's groups.

Sound Shore Medical Center of Westchester

The multidisciplinary team at the Solomon Katz Breast Center at Sound Shore Medical Center of Westchester in New Rochelle, realized there were large segments of at-risk women who were not being reached by conventional breast cancer screening efforts. Therefore, the Center formed a relationship with the County Health Department's Healthy Women Partnership to target this underserved population via mobile mammography. The program began in June 2002, has served more than 160 women, and has discovered a number of cancers.

Sound Shore Medical Center recently hosted a hormone replacement therapy panel. The panel consisted of health care providers that presented the pros and cons of HRT. The focus was to offer information, present a balanced view of HRT, and to assist women in their decision making. More than 200 people attended the presentation.

Thompson Health

Thompson Health in Canandaigua has expanded its patient navigation process to include personal contact from a breast health nurse with each woman who has a suspicious finding from the time of her mammogram or clinical breast examination through the time of diagnosis. Last quarter results show a 100% initial contact rate.

Thompson Health recently held a "Celebrating Life Recognition Day" for cancer survivors in the community. The keynote speaker was breast cancer survivor, Michael Samuelson, who is a health educator, author, and motivational speaker.

Vassar Brothers Medical Center

Patients have responded enthusiastically to an invitation to participate in the Multidisciplinary Breast Cancer Tumor Panel at Vassar Brothers Medical Center in Poughkeepsie. Before the patient's arrival at the meetings, the panel discusses the patient's specific case. The patient is then asked to join the panel. Relevant issues and discussion points are relayed to the patient, with encouragement to seek further information and ask questions.

Vassar Brothers Medical Center and the Sisters Network (an organization that addresses the breast health needs of African American women) held a free screening event in November 2002. Many of the women never had a mammogram and others had not had a mammogram within the past five years.



HANYS BCDP™ Advisory Board Update

The HANYS BCDP™ Advisory Board continues to have a full agenda. Advisory Board members are focusing on several high priority areas for workgroup efforts including identification of quality measures, outreach, education, and translation activities. Research and review of the current literature, together with outside expert consultant support, resulted in numerous publications and resource kits. All products of HANYS BCDP™ were disseminated to hospitals throughout New York State. They are also available through our Web site. The following is a brief summary of meetings and projects from the past year:

TOPIC: *The critical importance of good communication between patients and health care professionals.*

OUTCOME: HANYS BCDP™ Advisory Board committed to designing a *Physician-Patient Communication Resource Kit*. The Kit focuses on successful strategies for building on communication skills. The Kit is expected to be available soon.

TOPIC: *Creating an avenue for identifying undetected cancers among women in the workforce.*

OUTCOME: Due to the success of the Employee Mammography Inreach Program at North Shore-Long Island Jewish Health System, a HANYS BCDP™ sub-committee was formed to develop a resource kit. The *Employee Mammography Inreach Resource Kit*, developed in conjunction with the New York Organization of Nurse Executives, assists hospitals that wish to replicate the program within their facility. The Kit can be downloaded from HANYS' Web site at www.hanys.org/quality_index/Breast_Cancer_Project/resourcekits.htm.

TOPIC: *Breaking down language barriers.*

OUTCOMES: HANYS BCDP™ and the American Cancer Society (ACS) are translating the ACS/National Comprehensive Cancer Network *Breast Cancer Treatment Guidelines for Patients*, the *ABCs of Breast Health*, and the *ACS Guidelines for the Early Detection of Breast Cancer* into multiple foreign languages. ACS will make copies available to hospitals. HANYS BCDP™ will post the translations on its Web site.

TOPIC: *Assisting women through the health care system, along with providing guidance and support to ensure access to appropriate social and financial services.*

OUTCOME: The HANYS BCDP™ Advisory Board designed a *Breast Health Patient Navigator Resource Kit* modeled after the patient navigation program initiated at Harlem Hospital Center in New York City. The Kit is available on HANYS' Web site at www.hanys.org/quality_index/Breast_Cancer_Project/resourcekits.htm.

TOPIC: *Collaborative decision making.*

OUTCOME: Karen Sepucha, Ph.D., a guest speaker from Harvard University, discussed the importance of collaborative decision making between physicians and patients. Dr. Sepucha was instrumental in designing a "consultation recording" tool to assist patients and physicians in collaborative decision making for breast cancer care.



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Although patients are unique and the level of active participation they want may vary considerably, there are basic principles and recommended steps that can help patients identify their options, make choices, and become more prepared to face treatment outcomes. The following guidelines for communicating a breast cancer diagnosis, published in the spring 1997 issue of *Behavioral Medicine*, are based on a survey of doctors, patients, and nurses.

Principles:

- Only one person should be responsible for breaking the bad news.
- The physician's primary responsibility is to the individual patient.
- Tell the patient the diagnosis as soon as it is certain.
- Inform the patient in person, almost never by telephone.
- Make every effort to ensure privacy.
- Use eye contact and body language to convey warmth, sympathy, encouragement, and reassurance to the patient.

Recommended Steps:

- Allow uninterrupted time during the initial meeting.
- Assess the patient's understanding of the situation.
- Tell the patient the diagnosis and prognosis honestly in simple language, but not bluntly.
- Allow and encourage the patient to express her feelings, such as crying freely.
- Avoid giving a prognosis with a definite timescale.

Once the diagnosis and prognosis are communicated, the next step in addressing patient needs is threefold:

- First, identify and validate the patient's experience (i.e., nausea, fatigue, depression, sexual dysfunction, etc); and document the patient's experience within the framework of expected patient outcomes and response to treatment.
- Second, match the experience with a successful strategy for coping/reporting of symptoms.
- The third step is to pair the patient's need to an intervention option of her choice (i.e., report to health care provider, practice stress reduction techniques, attend a support group, access educational information via the Internet, outreach to local agencies and support services).

Once patients become involved in the decision-making process, they are in a better position to make informed, deliberate medical care choices. The result is enhanced physician-patient communication and better informed patients. In addition, patients report an increased sense of autonomy and greater satisfaction with their breast cancer providers and care.

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