

June 2002

Patient Autonomy: Improving Physician-Patient Communication in Breast Cancer Care

This article, which highlights the relationship between physicians and patients and their families, is the first in a three-part series. The article identifies issues that challenge physician-patient communication and explores strategies to address these concerns through physician-patient collaboration. The second article in the series will focus on patient decision support. Included will be strategies for eliciting patient experiences with respect to symptom management, fatigue, sexual dysfunction, depression, and other support issues for patients in crisis. The third article will discuss liability experiences and findings from the perspective of the insurance provider.

Breast cancer is the most frequently occurring cancer in women in the United States, and most of those women will equate the quality of their medical care with the degree to which their health care provider responded to their needs. This article focuses on improving the quality of medical consultations between breast cancer patients and physicians.

Data from the National Cancer Institute Surveillance, Epidemiology, and End Results (SEER)¹ project that, in 2002, breast cancer will remain the most frequently diagnosed female cancer. The number of new breast cancer cases is projected to surpass 203,500 in 2002—representing 31% of the female cancer diagnoses in this country.²

As age is the single greatest risk factor for breast cancer, the number of newly diagnosed female breast cancer patients will continue to increase as the population ages. The bright side of these findings is the survival data. Currently, the five-year survival rate for localized breast cancer is 96%, which has increased from 72% in the 1940s.

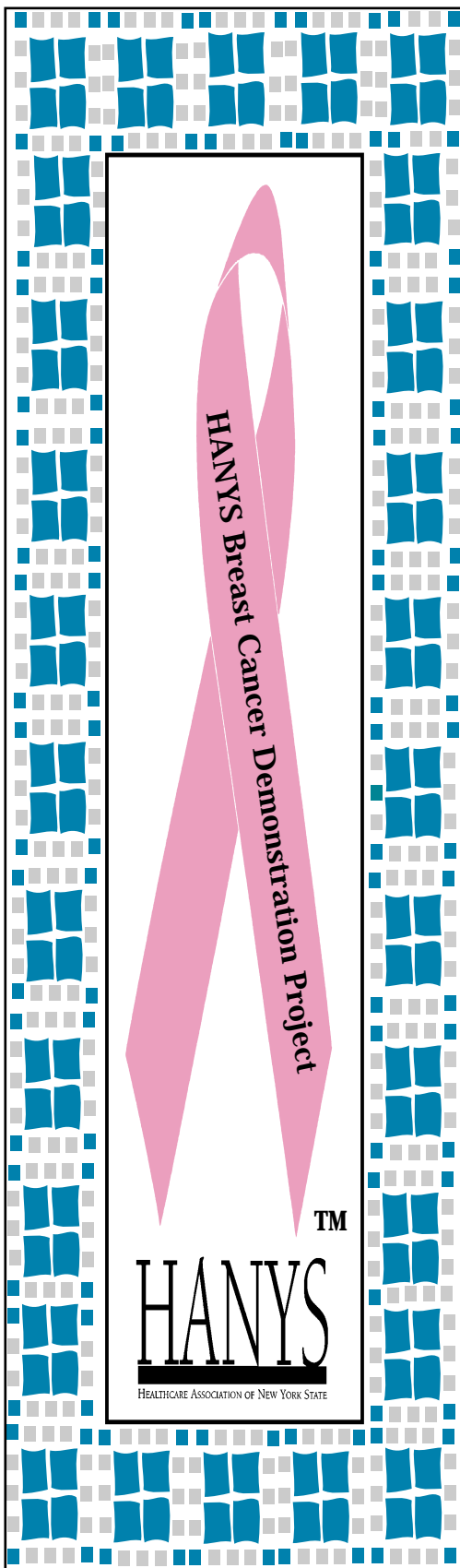
Changes in the organization of health care in the United States—including increased managed care, strict adherence to clinical guidelines, intense competition for patients and patient groups, and preferred provider contracts—have collectively and dramatically affected how breast health care is provided. Doctors across the spectrum of breast care service delivery have been impacted by these trends as they screen, potentially diagnose, subsequently treat, and oftentimes re-diagnose patients.

The role of the patient over the past two decades also has changed dramatically in the United States. Patients no longer passively receive health care services, but have assumed an active and assertive role as educated consumers, advocates for change, and proponents of cancer survivorship issues. For example, consumer

Continued on page 8

IN THIS ISSUE:

Patient Autonomy: Improving Physician-Patient Communication in Breast Cancer Care	Page 1
State's Early Detection Program to Include Coverage for Treatment Efforts Undertaken by HANYS Breast Cancer Demonstration Project™ (BCDP™)	Page 2
Cancer Awareness Network Publishes Information for Minority Populations in New York City	Page 2
National Cancer Institute Announces New Director	Page 3
Free Outreach Incentives Available	Page 3
What's Helpful on the Web?	Page 4
News from HANYS BCDP™ Sites	Page 4
Related Publications of Interest	Page 5





State's Early Detection Program to Include Coverage for Treatment

Effective October 1, the Health Care Workforce Recruitment and Retention Act of 2002 will make full Medicaid coverage available to women in the Healthy Women Partnerships (HWP) program who are found to have breast or cervical cancer or precancerous cervical conditions. The priority population for annual comprehensive screening examinations and services through the HWP program is women ages 40 and older who are at or below 250% of the Federal Poverty Guidelines and who are uninsured or underinsured.

The Act, which implements federal legislation passed in 2000, solves the program's decade-old dilemma of being unable to cover treatment for diagnosed women. It also alleviates some of the concerns providers may have had regarding potential uncompensated costs associated with the treatment of program clients.

Eligible individuals diagnosed before October 1, but who still need treatment, can enroll for coverage beginning October 1. Medicaid can pay medical bills incurred up to three months before the month of application for Medicaid, if the patient is otherwise eligible.

HANYS BCDP™ is working closely with Brad Hutton, Director of the New York State Cancer Services Program and a HANYS BCDP™ Advisory Board Member, to coordinate efforts to provide high quality breast health services while improving women's access to screening and overcoming barriers to treatment, with a particular emphasis on vulnerable populations.

The priority population for screening through the HWP program is asymptomatic, low-income, uninsured or underinsured women 40 years of age and older. Eighty-five percent of clients receiving program-funded services have no health insurance.

The federal Centers for Disease Control and Prevention and the New York State Department of Health (DOH) fund 53 HWPs within the state to coordinate screening and diagnostic services at the local level. More than 800 clinical providers participate

in the program in New York State, providing screenings to approximately 60,000 HWP program clients each year.

American Cancer Society "Gold Standard" for Early Breast Cancer Detection:

- mammograms,
- clinical breast examinations, and
- breast self-examinations.

HWP clients are screened according to American Cancer Society (ACS) guidelines, which reflect that early detection of breast cancer coupled with timely follow-

up remains the most effective method to ensure more treatment options and decrease mortality. ACS has put forth a triad of screening techniques that women should undertake for early breast cancer detection. All women age 40 and older should:

Efforts Undertaken by HANYS Breast Cancer Demonstration Project™ (BCDP™)

HANYS BCDP™ objectives include developing strategies to decrease fragmentation in services, enhance health care quality across the continuum, and improve access to care with a particular emphasis on vulnerable populations. Improving communications with patients is integral to the project.

To provide strategies that attend to patients' needs and perspective, a committee of HANYS BCDP™ Advisory Board members will consider the issue of patient autonomy in breast cancer care. This committee has agreed to review and evaluate the current literature, symposia, videos, CD-ROMs, and research addressing this topic. After evaluating the material, the committee plans to develop a best practice tool kit, which will enhance patient decision-making and be easily utilized in physician offices, hospitals, and other health care settings. The general topics will focus on patient communication through preparation, education, customization, and exchange.

- have an annual mammogram;
- have an annual clinical breast examination by a health care professional; and
- perform monthly breast self-examinations.

ACS recommends that women ages 20-39:

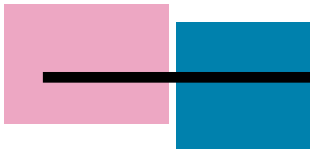
- have a clinical breast examination every three years; and
- perform monthly breast self-examinations.

ACS provides skills refresher programs (at a nominal cost) for nurses who provide clinical breast examinations for HWP program clients. This skills refresher program focuses on clinical breast examination techniques and emphasizes that the best opportunity to teach patients to correctly perform breast self-examinations is when a provider is performing a clinical breast examination.

The ACS cervical screening guidelines suggest annual pelvic examinations with Pap smear tests for women beginning at age 18. After three or more consecutive satisfactory normal yearly examinations, Pap smear tests may be performed less frequently at physicians' discretion.

Through March 2002, 1,376 cases of invasive breast cancer, 338 cases of in situ breast cancer, 34 cases of invasive cervical cancer, 963 precancerous cervical lesions, and 14 other gynecologic cancers have been diagnosed among clients in the HWP program. The breast cancers that are detected among clients returning to the program are more often found at an earlier stage, when treatment is more successful. This highlights the importance of encouraging women to return to the program for the screenings in subsequent years. Fifty-three percent of breast

Continued on page 7



Cancer Awareness Network Publishes Information for Minority Populations in New York City

The Cancer Awareness Network for Immigrant Minority Populations (CANIMP) has produced a new *Cancer Services Catalogue* for New York City residents. The *Catalogue* is a comprehensive listing of cancer-related services available in the city. Health care providers can use it to locate services for non-English and English-speaking patients.

The Center for Immigrant Health and the Kaplan Comprehensive Cancer Center of the NYU School of Medicine created CANIMP with funding from the National Cancer Institute to respond to under-utilization of cancer services by immigrant and minority populations. CANIMP focuses on bridging the gap between immigrant communities and cancer researchers in the fields of lung, prostate, breast, and cervical cancers. More information about CANIMP is available at www.med.nyu.edu/cih/cancer.

The CANIMP *Cancer Services Catalogue* indexes resources in a user-friendly format by program name, service, location, and language capability. The *Catalogue* concentrates on organizations that provide services in Chinese, Creole, English, French, and Spanish; fewer resources are listed for other languages.

CANIMP expects to initiate a Lay Health Worker Pilot Program this year to reduce socioeconomic, linguistic, and cultural barriers to cancer care services in Haitian, English-speaking Caribbean, Latino, Korean, and Chinese communities of New York City. Workers will be trained in cultural competence and will be members of the targeted communities. They will serve as liaisons between the immigrant community and “cancer control” services. This role includes delivering cancer education, disseminating information, and educating clients on methods

CANIMP Cancer Services Catalogue

The *Catalogue* covers services in:

- Breast cancer
- Breast cancer/screening centers
- Cancer—all types
- Financial assistance/insurance
- Housing
- Lung cancer
- Lung cancer/smoking cessation
- Lung cancer/support group
- Prostate cancer
- Transportation
- Language capabilities include: African, Arabic, Chinese*, Creole*, French*, English*, Greek, Guinnesse, Hebrew, Italian, Japanese, Korean, Russian, South Asian, Sign, Spanish*, Thai, Ukrainian, Vietnamese, Yiddish

*The *Cancer Services Catalogue* concentrates on services in these languages.

of maximizing their provider-patient communication and in requesting interpretation services. Information regarding CANIMP's Lay Health Worker Pilot Program may be accessed at www.med.nyu.edu/cih/cancer/layhealth.html.

The *Cancer Services Catalogue* is available at: www.med.nyu.edu/cih/cancer/healtheducation.html (this site is updated frequently). For more information regarding the *Catalogue*, organizations may contact the Center for Immigrant Health at (212) 263-8783.

National Cancer Institute Announces New Director

On December 6, 2001, President George W. Bush appointed Dr. Andrew von Eschenbach to head the National Cancer Institute. Dr. von Eschenbach graduated Georgetown University in 1976 and began work at M. D. Anderson Cancer Center, where he served as surgeon, Director, Professor of Urology, and consulting Professor of Cancer Biology.

The formal investiture ceremony was held February 4 at the National Institutes of Health, National Cancer Institute in Bethesda, Maryland. Dr. Harold Freeman, who chairs the Cancer Panel: Cancer Research in a Social Context, spoke. Dr. Freeman is Director of Surgery at North General Hospital, New York City; Professor of Clinical Surgery, Columbia University College of Physicians and Surgeons; and Chairman of HANYS BCDP™. A leading authority on the interrelationships of race, poverty, and cancer, Dr. Freeman spoke of the toll and burden of cancer on the under-served and underprivileged.

In his opening remarks, Dr. von Eschenbach stated, “Discovery, development and delivery of state-of-the-art cancer care and control requires collaboration.” He pledged to create collaborations among federal and state agencies, public and private institutions, cancer organizations, and cancer survivors, noting that these groups are crucial in accelerating the process of discovery of findings to implementation of care.



Free Outreach Incentives Available

Gifts In Kind International provides non-profit organizations with free products and goods that can be used to encourage patients to come in for services. Gifts In Kind International receives donations from the private sector and serves as an intermediary to the charitable sector. Products and goods available through Gifts In Kind International include personal care products, cosmetics, dental hygiene products, clothing, office equipment and supplies, technology product services, educational materials, and sports equipment. There is an annual registration fee, and qualifying organizations are required to pay a nominal administrative fee to cover shipping and handling.

HANYS BCDP™ has ordered products through Gifts In Kind International and disseminated them to project sites to bring new, returning, or hard-to-reach patients in for services.

Gifts In Kind International can be reached at www.giftsinkind.org or at (703) 836-2121. The National Association for the Exchange of Industrial Resources has similar products and can be reached at www.naeir.org or at (800) 562-0955.

What's Helpful on the Web?

You can access these and other resources on HANYS BCDP™ Web page at www.hanys.org/tools/Breast_Cancer_Project/links.htm

HEALTHY WOMEN PARTNERSHIP

New York State Department of Health

www.health.state.ny.us

Information regarding the Healthy Women Partnership program can be accessed through this site by clicking on “Info for Consumers,” “Cancer Services,” and “Breast and Cervical Cancer.” Information includes an overview and benefits of the program. Partnerships are listed by county and descriptions include the name of the partnership, the address, telephone number, and a contact person. This site also includes a map showing the location of mammography facilities by specific counties.

New York State Division of Women

www.women.state.ny.us

The Division of Women serves as an advocate for women's health issues and acts as a liaison between women of New York State and the Governor. The Web site features a newsletter published by the Division of Women. The November 2001 issue highlights the Healthy Women Partnership program, along with other topics specific to women's health issues. This newsletter may be accessed at: www.women.state.ny.us/pdfs/focus2.pdf.

GENERAL BREAST CANCER INFORMATION

The Breast Care Site

www.thebreastcaresite.com/imaginis

The Breast Care Site is a consumer-oriented Web site that provides information on “activities of daily living,” i.e., tips on getting back to working outside of the home, and on where and how to locate personal items that fit properly following breast

surgery, such as brassieres, breast forms, and swimsuits. It also helps women interpret their health insurance information regarding coverage on procedures and personal items, discusses intimacy issues, and includes personal stories of survival and the trials that women face in confronting breast cancer.

Women's Information Network (WIN) Against Breast Cancer www.winabc.org

WIN's goals include increasing women's access to breast cancer screening, breast cancer education, and peer support, and serving as a general resource for women. WIN is active in lobbying—urging policymakers to continue the fight against breast cancer through funding for programs and research. WIN works to empower women through education regarding physical changes occurring within their bodies, defining medical terms, and providing access to a personal profiler. Women enter data specific to them (and their diagnosis) and receive a profile with information and treatment options specific to their diagnosis.

Oncology Channel

www.oncologychannel.com/breastcancer

The Oncology Channel Web site is a consumer-oriented site that offers information on the latest news pertaining to breast cancer, specific conditions, and symptoms. This site also enables patients to speak with other patients and a physician in designated chat rooms. Visitors to this site may also obtain a list of suggested questions to ask their doctors regarding specific cancer diagnosis, available treatment, surgeries, and clinical trial options.

Y-ME National Breast Cancer Organization

www.y-me.org

The Y-ME site is a support and information resource for people whose lives have been affected by breast cancer. It has telephone numbers for the Y-ME National Breast Cancer Hotline in English and Spanish and an archive of Internet resources. The Web site offers communication in both English and Spanish.

Continued on next page



News

FROM HANYS BCDP™ SITES

Arnot Ogden Medical Center

The Health Center for Women at Arnot Ogden Medical Center in Elmira has opened a new satellite breast imaging facility that features a mobile positron emission tomography (PET) scanner. PET is a non-invasive imaging procedure that produces cross-sectional images of the metabolic function of the body. This is in contrast with magnetic resonance imagery and computerized tomography, which show anatomical structure.

Along with state-of-the-art equipment, the Center focuses on creating a relaxing environment to decrease patient stress and anxiety, including massage therapy, relaxing music, aromatherapy, and comfortable décor.

Benedictine Hospital

The Breast Center at Benedictine Hospital in Kingston is hiring and training a breast health navigator. Using the HANYS BCDP™ *Breast Health Navigator Program Best Practice Guide*, this person will work with individual women and groups to facilitate access to mammography screening and ensure a more comfortable mammography experience. The role includes outreach to low-access communities, arranging transportation, guiding eligible patients to the Healthy Women Partnership

Continued from previous page

PROVIDER-PATIENT COMMUNICATION

American Academy on Physician and Patient

www.physicianpatient.org

The American Academy on Physician and Patient (AAPP) is a society dedicated to research, education, and professional standards in patient-doctor communication. Its goal is to help clinicians and patients, and learners and teachers relate more effectively. The AAPP Web site offers a monthly vignette, written by health care providers, to help providers think about potential responses to difficult communication dilemmas. There are suggested responses that may aid providers in enhancing communication with patients. This site also highlights the latest research in the health communication field and is a resource for providers interested in educational communication information.

Bayer Institute for Health Care Communication

www.bayerinstitute.com

Bayer Institute for Health Care Communication is dedicated to enhancing the quality of health care by improving the communication between providers and patients through education, research, and advocacy. This Web site highlights services Bayer can provide to health care organizations to assist clinicians in developing effective communication skills.

program, and tracking the effectiveness and outcomes of the navigator position. Other goals include establishing a breast cancer learning library and providing cancer screening and prevention education.

The Breast Center is also utilizing mammopads, which are non-radio interfering foam devices that cushion the pressure of mammography and do not interfere with picture quality. The Center is also exploring the use of complementary medicine techniques to increase comfort and decrease anxiety during mammography screening.

EE Thompson Hospital

EE Thompson Hospital implemented a pilot project to evaluate the effectiveness of expanding services by creating an evening screening program. The pilot project was a success and the official screening program began in January 2002. Evening screening utilizes a fast-track approach. Mammography films are “batch” read by the radiologist the next day. This allows radiologists to read mammograms more quickly. Patients with normal results receive notification by mail within a week. Patients who must be called back for additional mammography views or ultrasound are contacted immediately.

A formal survey reflected that patients surveyed appreciate the option to choose between this fast-track approach and the traditional screening mammogram. This innovative scheduling and use of existing space and equipment added 48 new appointments each week, which decreased patients' waiting time for screening mammograms by three months.

New York Hospital Medical Center of Queens

The New York Hospital Medical Center of Queens (NYHMCQ) Breast Cancer Center is initiating a Breast Cancer High Risk Assessment Center. Center physicians will evaluate women's risk potential for breast cancer and, if a woman is found to have increased cancer risk factors, counseling will occur and oral and written information on genetic testing will be provided. Women will have the option of testing to evaluate breast cancer gene BRCA1 and BRCA2 gene alterations. Women who choose the testing can now receive it through an arrangement between The Breast Cancer Center at NYHMCQ and a genetic testing facility. Once the physician receives the results, another counseling session is scheduled with the patient to deliver the results. The Breast Cancer Center secured a grant that covers the cost of genetic counseling and BRCA1 and BRCA2 testing for high-risk women.

St. John's Riverside Hospital

St. John's Riverside Hospital in Yonkers opened a new Breast Imaging Center with women's imaging services located in one area. This better serves the population by eliminating travel between various departments. The comfortable setting includes new mammography suites, a bone density suite, Internet access

Continued on page 6



Continued from page 5

to research information for patients, and a breast health library filled with books and publications related to women's health issues, with a particular emphasis on breast health and cancer.

Vassar Brothers Hospital

Vassar Brothers Hospital in Poughkeepsie recently opened The Dyson Center for Cancer Care. Within the Dyson Center, the Murphy Center for Radiation Oncology provides treatment using the newest linear accelerators (a therapy delivery device). Intensity modulated radiation therapy will soon be available.

The Dyson Center is also creating the "Breast Care Center of Excellence." The Center's goals are to decrease service frag-

mentation and waiting time. The Breast Care Center of Excellence will have a breast surgeon on staff and an R2 Image Checker for mammography readings (a computerized mammography reading device). Services will be coordinated to decrease the amount of trips a patient has to make to the Center to receive care. Vassar Brothers Hospital is using grant funding to hire a patient navigator to help women find their way through the health care system. The Center also offers a wide array of cancer rehabilitation services, i.e., life skill management, fatigue management/energy conservation, stress management/coping skills, pain management, and a lymphedema management program.

Related Publications of Interest

Building bridges between physicians and patients: results of a pilot study examining new tools for collaborative decision making in breast cancer

Patients increasingly want to become involved in their health care decisions but may need time to absorb a breast cancer diagnosis and consider the options their physician discusses with them. This article examines a pilot study that utilized "consultation recording," a tool for collaborative decision-making in breast cancer care. This five-step process includes: contracting, agenda, mapping, commitments, and debriefing. Researchers found an increase in quality of treatment decisions and increased quality of satisfaction with the consultation.

Sepucha, K. R. Belkora, J. K., Tripathy, D., Esserman, L. J. *Journal of Clinical Oncology*, March 2000, 18(6): 1230-8

Doctor-patient communication patterns in breast cancer adjuvant therapy discussions

This article discusses an in-depth study that identifies variables that affect overall patient comprehension and satisfaction with physician communications. Fifty patients and 15 oncologists participated. Researchers found that patients who spoke more and asked more questions were more knowledgeable, and patients whose oncologist used more emotional dialogue were less knowledgeable, but had higher satisfaction rates. The authors identify methods that can enhance physician-patient communication patterns.

Siminoff, L. A., Ravdin, P., Colabianchi, N., Saunders-Sturm, C. M. *Health Expectations*, 2000, 3: 26-36

Narrative Medicine: A Model for Empathy, Reflection, Profession, and Trust

This article discusses how narrative medicine may help providers achieve empathetic and effective therapeutic relationships with patients. Narrative medicine adopts traits of narrative competence; which are the ability to acknowledge, absorb, interpret, and act on the stories and plights of others.

Charon, R. *Journal of the American Medical Association*, 17 October 2001; 286(15): 1897-1901

Patient-Health Care Provider Communication During Chemotherapy Treatment: The Perspective of Women with Breast Cancer

This article describes women's perspectives on how patient-provider communication, patient-provider relationships, and being an informed patient have affected their cancer care experience. The article outlines practice implications.

Bakker, D., Fitch, M., Gray, R., Ree, E., Bennet, J. *Patient Education and Counseling* 2001, 43:61-7

Continued from page 2

cancers found among new clients are detected at an early stage (in situ or stage 1), and 69% of cancers detected among returning clients are found at an early stage.

According to Anne Marie Linek, R.N., Program Coordinator for the HWP of Ontario and Yates counties, numerous women have benefited from this program due to the participation of many community health care providers in these counties. Ms. Linek stated that women have repeatedly told her they are grateful that the program exists and that these health services are available to women without insurance. "The Healthy Women Partnership program has helped us screen women and find cancers that may have otherwise been left undetected," Ms. Linek said.

**American Cancer Society
Clinical Breast Examinations
Skills Refresher Program:**

- Education for nurses who provide clinical breast examinations in the HWP program.
- Nursing Continuing Education Units available.
- For more information, please contact: Susan Booth, Breast Health Administrator, ACS, (518) 438-7842, extension 329.

Judy Koles, Nurse Coordinator at The Women's Health Center in Huntington Hospital said, "The women very much appreciate that New York State, and Suffolk County specifically, take the initiative to see that these women are screened for breast cancer."

The HWP program educates women, many of whom have never had a mammogram, to go for a screening mammogram. At the screening visit, one goal is to educate women to practice monthly breast self-examinations and continue regular mammogram screenings.

The HWP program reimburses for the following screening tests: clinical breast examinations, mammograms, pelvic examination with Pap smear, and associated cytology. When a breast abnormality is found in an HWP participant, the HWP program reimburses for the following diagnostic procedures: ultrasound, diagnostic mammogram, fine needle aspiration, needle localization, core, incisional, excisional and stereotactic biopsies and their associated pathology, surgical consultation, and anesthesiologist fees. When a cervical abnormality is detected in an HWP participant, the program reimburses for colposcopy with or without cervical biopsy and its associated pathology, and gynecologic consultation.

Expanded coverage now includes compensation for liquid-based Pap smears, and pre-operative testing, which includes a

New York State Cancer Services Program Maximum Allowable Reimbursement Rates April 1, 2002 - March 31, 2003	
<u>SCREENING SERVICES</u>	
Assessment, education and clinical breast exam	\$ 32
Assessment, education, and pelvic examination with Pap smear	\$ 32
Screening mammogram	\$ 76
<u>DIAGNOSTIC SERVICES</u>	
Diagnostic mammogram	\$ 70
Short visit—repeat clinical breast exam or pap smear	\$ 15
Ultrasound	\$ 62
Fine needle aspiration	\$ 136
Ultrasonic needle localization	\$ 84
Core biopsy	\$ 99
Incisional biopsy	\$ 300
Excisional biopsy	\$ 393
Stereotactic biopsy procedure	\$ 536
Mammographic needle localization	\$ 71
Colposcopy	\$ 96
Colposcopy—directed biopsy	\$ 113
Surgical consultation/second opinion	\$ 84
Anesthesiologist services	\$ 150
<u>PRE-OPERATIVE PROCEDURES</u>	
Chest x-ray	\$ 31
Complete blood count	\$ 10
Electrocardiogram	\$ 24
<u>PATHOLOGY</u>	
Pap smear cytology, conventional	\$ 14
Pap smear cytology, thin preparation	\$ 25
Fluid cytology, other than vaginal/cervical	\$ 45
Surgical pathology, gross and microscopic	
Exam of breast, or cervical tissue	\$ 89

complete blood count, electrocardiogram, and chest x-ray.

Reimbursement is provided following statewide program reimbursement rates that are based upon Medicare rates.

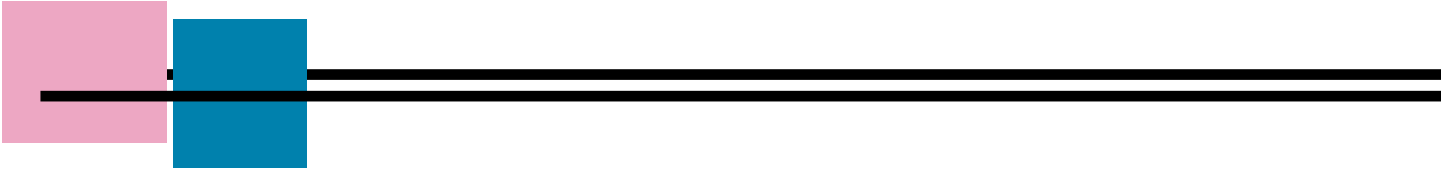
Hospitals can enroll by contacting the HWP in their area. A complete list of contacts for each partnership can be found on the Internet at: www.health.state.ny.us/nysdoh/consumer/cancer/main_1.htm.

Hospitals must agree to follow HWP program policies and work with the HWP to submit data. There is no formal application process. The agreement is between the provider and the specific HWP.

Hospitals interested in more information about enrolling in the HWP program should contact DOH at (518) 474-1222.

HANYS BCDP™ site hospitals that participate in the Healthy Women Partnership program include:

Arnot Ogden Medical Center, Elmira; Benedictine Hospital, Kingston; Crouse Hospital, Syracuse; FF Thompson Hospital, Canandaigua; Huntington Hospital, Huntington; Lutheran Medical Center, Brooklyn; New York Community Hospital, Brooklyn; North General Hospital, New York; Sound Shore Medical Center of Westchester, New Rochelle; Southside Hospital, Bay Shore; St. John's Riverside Hospital, Yonkers; and Vassar Brothers Hospital, Poughkeepsie



Continued from page 1

panels convened through the National Cancer Institute (NCI) Director's Consumer Liaison Group and other programs sponsored by the National Institutes of Health have joined patient advocates with the scientific community in the grant review process.

Patients traditionally equate the quality of the medical care they receive with the degree to which their health care provider responds to their needs.

Simply hearing a breast cancer diagnosis can be traumatic. As one patient said, "All I heard the doctor say was that I have breast cancer. I don't remember one word after that. I know his mouth was moving, and the words were coming out, but I just don't remember what he said."

This emotional distress can result in clinical depression and post-traumatic stress disorder, which further confound the choices and decisions patients make as they seek medical care and treatment. During this time of personal crisis, confusion, and dilemma, it is no surprise that many patients seek second and even third medical opinions as they struggle to understand their diagnosis and make choices that will result in the best possible outcome.

Dan Labriola, author of *A Guide to Choosing Your Health Care Provider*³, cautions patients that "not all providers are created equal." He notes that as patients seek "the best" in their care and medical treatment, they seek the confidence of knowing they made the right decision and that their health care provider understands their needs. Of equal importance, yet rarely voiced by patients, is their need to feel less like victims and more like active participants in their care. Patients want to maintain their sense of dignity, gain control, and have an open exchange with health care providers.

The quality of medical consultations between breast cancer patients and physicians can be greatly enhanced by the tailored and timely presentation of information to breast cancer patients.⁴ There is considerable recent evidence that the physician-patient exchange is affected by a host of non-biomedical factors. Some studies report that physicians communicate with and react to a patient differently depending on the patient's age, gender, ethnicity, and social class. Additional studies conducted at the University of Kentucky College of Medicine suggest that a woman's perception of positive physician interpersonal skills during the diagnostic consultation results in later psychological satisfaction with the care provided.⁵

Research has demonstrated that patient coaching and interactive education can help patients become more involved in health care decision-making and successfully navigate the health care system through diagnosis, treatment, and follow-up care, thus improving their health outcomes.⁶

Successful interventions are characterized by:

Preparation: Teach patients how a crisis affects concentration and the thinking process, including the interpretation of information and decision-making strategies. Someone who can serve as a listener and recorder of information should accompany a patient. A patient notepad enhances opportunities for the patient to express concerns, take notes, and proactively participate in the health care process.

Education: Resources such as Web sites, CD-ROMs, books, videotapes, agencies, support groups, medical suppliers, and coalitions can help guide patients on their journeys and decrease their sense of isolation.

Customization: Give patients resource materials that are relevant to their concerns and inform patients about what are "normal" or "expected" results of blood work, test values, and side effects.

Exchange: Offer patients an opportunity to participate in a support group of peers where a commonality of diagnosis and coping strategies are shared.

Patient Navigator: Introduce patients to a staff person who will assist them as they proceed through their diagnosis, surgery, and treatment, and return to their activities of daily living.

Timeliness: Enable patients to view, read, or listen to information at their own pace, helping them become informed consumers and to better engage in the decision-making process.

¹*Cancer Statistics Review, 1973-1998*, SEER Program, Division of Cancer Control and Population Sciences, National Cancer Institute, 2001

²American Cancer Society, *Cancer Facts and Figures 2002*

³Labriola, D. *A Guide to Choosing Your Health Care Provider*, Roseville, CA, Prima Publishing, 2000

⁴Sepucha, K.R., Belkora, J.K., Tripathy, D., Esserman, L.J. *Journal of Clinical Oncology*, 18 March 2000; (6) 1230-1238

⁵Mager, W., Andrykowski, M., *Psycho-Oncology* 11 January 2002; (1), 35 - 46

⁶California Health Care Foundation, January 2000

HANYS BREAST CANCER DEMONSTRATION PROJECT™ STAFF

HANYS' Division of Quality and Research Initiatives
One Empire Drive, Rensselaer, NY 12144
(518) 431-7661

DR. HAROLD FREEMAN
Advisory Board Chair

KATHLEEN CICCONE
Principal Investigator

PAVANI RANGACHARI
Technical Data Analyst

CONSTANCE BAIRD
Project Director

DIANE KOPECKI
Nurse Education Coordinator

JACKIE ALBERT
*Health Policy Clinical
Researcher*

LYNNE WILLIAMS
Executive Assistant