
BENEDICTINE HOSPITAL

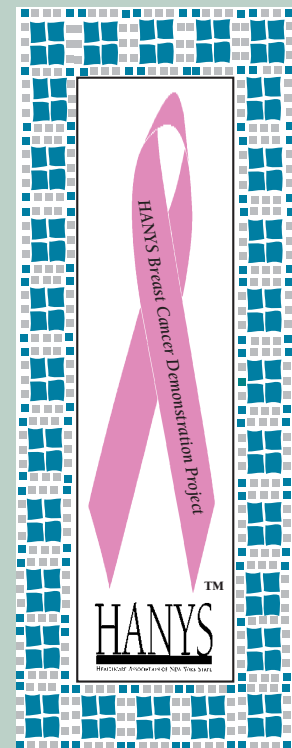
Breast Cancer Community Outreach to Vulnerable Populations

Background: Community Outreach Strategies

Recent studies conclude that the decrease in breast cancer mortality in the United States is attributable in part to increased breast cancer screening. A key reason behind the increase in screenings is the growth in targeted outreach programs that encourage women to participate in breast self-examination, obtain mammography screenings, and seek treatment when there may be a potential health problem. Experience and research indicate that community outreach programs must be tailored to the populations that need the services.

Perhaps the most challenging outreach programs are those for more vulnerable or hard-to-reach populations such as low-income and minority women, elderly women, women with disabilities, women in rural areas, women from diverse cultures and ethnic backgrounds (e.g. Hispanic, Muslim, Asian, etc.), and migrant workers. Research has found that there are real and perceived barriers to accessing breast cancer screenings and mammography for these groups.

Because different populations have different needs and face unique barriers, health care providers must employ a wide range of strategies to reach the various target populations. Research shows that programs conducting education and outreach programs at local organizations, churches, and other community gathering places can be successful in increasing screenings among low-income and minority populations.



Best Practices Strategy Guide



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The Healthcare Association of New York State (HANYS) Breast Cancer Demonstration Project (BCDP™) was established to develop, implement, and evaluate best practice models for integrated breast health services. Founded in 1998, HANYS BCDP™ has partnerships with multiple hospitals, health care systems, and health care organizations throughout New York State. The New York State Assembly and the federal Centers for Disease Control and Prevention fund the Project.

In partnership with its health care sites in New York State and guided by an Advisory Board, the HANYS BCDP™ seeks to examine the many aspects of cancer services, from community outreach to clinical integration to compassionate end-of-life services. It also serves as a learning opportunity for hospitals and members to pilot projects and share successes and experiences with their breast health initiatives.

Working with hospitals, health care systems, and health care organizations, the HANYS BCDP™ seeks to:

- *increase access to care;*
- *decrease barriers to care;*
- *identify best practice strategies; and*
- *promote patient autonomy and quality of life.*

To facilitate targeted, culturally relevant community outreach programs, HANYS BCDP™ developed and distributed *Mammography Guides* to hospitals that are participating in the Project. These guides, developed with data from the Inforum® Claritas database and input from the HANYS BCDP™ Advisory Board, were tailored to ZIP Code areas in each community. This demographic breakdown provided hospitals with an overlay of the types of populations in their service areas and offered specific strategies to employ for conducting outreach to these populations.

Benedictine Hospital, a 222-bed hospital located in Kingston, New York—one of the HANYS BCDP™ Advisory Board hospitals—has implemented effective, innovative outreach strategies for vulnerable populations in its area based, in part, on the information provided by HANYS BCDP™.

The Benedictine Experience

A Tradition of Caring at Benedictine

New York State has the second highest incidence of women diagnosed with breast cancer in the nation, and there are a number of communities served by Benedictine Hospital that have an even higher-than-expected rate of breast cancer plus an above-national-average incidence of breast cancer among men. In response, nearly a decade ago Benedictine Hospital began a comprehensive cancer prevention and support initiative.

Benedictine's tradition of caring is evident in and woven throughout its cancer support program. According to Barbara Sarah, the founder and current Director of the Benedictine Hospital Oncology Support Program, "We have a program unlike any other—just take a look."

Ms. Sarah said that the Benedictine Hospital Oncology Support Program's success is manifested in many ways, but none are more dramatic than in the Healing Arbor on the Rondout River in Kingston. Created by The Healing Circle visual arts class six years ago and funded by the Benedictine Hospital Oncology Support Program, this artistic structure sits in the middle of the city of Kingston and is a symbol of caring and remembrance for the community. It continues to be used as a focal point for cancer-related initiatives. It was the site for the kick-off of Benedictine's month-long activities for National Breast Cancer Awareness Month and the announcement of special grant funding earmarked for the Benedictine Hospital Cancer Center.

Volunteers and part-time professionals established a cancer support program for individuals with breast cancer at Benedictine Hospital eight years ago. The program, which initially focused only on breast

The Healing Arbor in Kingston is a symbol of caring and remembrance for the community.



cancer, has grown to include all cancer patients, their families, and friends. Today, the Benedictine Hospital Oncology Support Program offers a wide variety of programs and services including support groups, arts, nutrition and healing programs, education, and hospital visits. The Program's innovations include:

Nurturing Neighborhood Networking Program: Initiated in 1998, the Nurturing Neighborhood Networking Program links trained cancer survivors with persons newly diagnosed with cancer. These “nurturers” provide comfort, support, and assistance to other community members. In its first four years, the program trained 30 nurturers and supported hundreds of individuals diagnosed with cancer. Originally begun for breast cancer, the program was expanded in 2001 to include men and women with all types of cancer.

Healing Circle Improv: This improvisational group dramatizes the thoughts and feelings of cancer patients and performs for oncology patients, their families, and friends in the hospital and at homes. Recently, this group has traveled to other support organizations in New York, offering advice and counsel for initiating similar groups.

The Kids Connection: Designed for children who have a family member living with cancer, this initiative offers support and education through special children's programs and individual and family counseling.

Focus on Healing Through Movement & Dance (The Lebed Method): This therapeutic exercise program was created by two physicians and a dance movement specialist for cancer survivors. It also has been used for those with chronic illnesses.

The Celebrate Life! Newsletter: Benedictine distributes this bi-monthly newsletter to patients, family members, and staff whose lives

FOCUS GROUPS:

- *Hospital employees and volunteers*
- *Senior citizens*
- *Adolescents and young adults*
- *Faith community*
- *Migrant workers*
- *Prison population*

MAMMOGRAPHY INCENTIVES USED:

- *Informational coupons*
- *Raffle tickets*
- *Free transportation*
- *Reminders about appointments*

have been touched by cancer. It includes columns by physicians, cancer information, articles by support program staff, reader contributions, a program calendar, recipes, and announcements of special events.

While these programs are sponsored and conducted by Benedictine Hospital, a tremendous amount of work is also being done by and with community members and advocates. One such project is the Mid-Hudson Options Project, which offers breast cancer support, health information, and advocacy to ensure that all women have access to high quality health care, information to make informed health choices, and the support they need when making important health care decisions. One of its principal programs is the Companion/Advocate program funded through a New York State Department of Health (DOH) grant. This program trains volunteers to accompany breast cancer survivors to doctor appointments and to help patients gather information. Other programs conducted by Mid-Hudson Options Project include:

- an e-mail newsletter;
- a breast cancer resource guide;
- an annual complementary medicine conference;
- a Web site;
- a registry for women using surgery only as their cancer treatment;
- computer training on how to locate the best resource information on cancer; and
- breast cancer risk reduction workshops.

Hope Nemiroff, the volunteer advocate who runs the Mid-Hudson Options Project, works closely with Benedictine staff and is part of Benedictine's breast health outreach team.

The Benedictine breast health program is a partnership run by a team of part-time health professionals, patients, volunteers, and advocates. It is a collaborative effort between the hospital and its community members. The core team consists of:

- two part-time breast health navigators;
- one part-time oncology support coordinator;
- a coordinator for the Nurturing Neighborhood Networking Program; and
- an advocate who leads the Companion/Advocates program.

In addition to being advocates and professionals, most of the team members are cancer survivors themselves. They bring the patient perspective and passion, along with professional acumen, to their work. They are dedicated, driven, and committed to making a difference in

the lives of their communities—through increased personal surveillance and mammography screening and through support, comfort, and compassion for those recently diagnosed with breast cancer and those living with breast cancer.

One of the more remarkable aspects of the Benedictine Hospital initiative is that most of the work has been done through the dedication and support of volunteers, with minimal hospital staff effort. When Susan Spadanuta and Ujjala M. Schwartz joined the Benedictine team as part-time breast health navigators, a comprehensive cancer support program was already in place and their focus was to complement the program through increased community outreach.

Benedictine’s Focus on Community Outreach

Since becoming part of the breast health team and identifying outreach as a priority, the Benedictine breast health navigators have done considerable networking with other organizations. Since they can be in two places at one time, they accept all invitations to present before community groups and make contacts throughout the hospital’s service area.

In taking a close look at their community characteristics and breast cancer incidence and working with HANYS, the breast health team zeroed in on the following populations for its community outreach efforts:

Hospital Employees and Volunteers. Through its employee breast health project, called “Caring for Our Own Community,” Benedictine Hospital’s first audience for outreach was its own employees. Department by department, hospital employees and volunteers are taught how to do breast self-examinations and encouraged to receive a mammogram. The hospital waives all copayments and fees for employees who have a mammogram conducted at Benedictine.

Senior Citizens. Through a multi-pronged approach and ambitious schedule, the breast health navigators are going out into the community and educating senior citizens about breast health screening and demonstrating breast self-examinations. The navigators provide informational coupons, raffle tickets, free transportation, and reminders about appointments as incentives to come to the hospital for a mammogram. From the local Benedictine senior citizens club called BeneCare, to the more than 40 seniors’ clubs located throughout Ulster County, the breast health navigators are spreading the word, using materials from the New York State DOH and the American Cancer Society and offering giveaways like emery boards and magnets. At one event—the Golden Gathering sponsored by New York State Senator Stephen Saland (R-Poughkeepsie)—Benedictine was able to speak to

LESSONS LEARNED:

- *Reach out to the community—do not expect the community to reach out to you.*
- *Cultivate relationships with community organizations.*
- *Involve patient and families.*
- *Provide “safe places” for discussions.*
- *Understand different cultures and their unique needs.*

1,200 seniors about cancer screenings. In addition, the Benedictine breast health team is tracking results by identifying who is coming to the hospital based on the team’s outreach efforts in the community.

Adolescents and Young Adults. In collaboration with the Board of Cooperative Education Services (BOCES) New Visions program, Benedictine Hospital is teaching high school students about breast self-examination and breast cancer prevention. The New Visions students—a select group of students who are interested in health careers and “intern” at hospitals—help conduct community outreach among their peers through question-and-answer sessions on topics such as “normal” breast characteristics and the importance of monthly self-examinations. Students in the New Visions program also are taught how to be effective advocates—the Benedictine breast health team brings each year’s students to Albany to learn about lobbying and advocating for key health care issues. Benedictine’s breast health team conducts additional activities with schools, and students are encouraged to bring information home for their mothers. The hip-hop band, Energizer Dance Troupe, performed at Benedictine’s recent “Celebrate Life!” breast cancer awareness month special event at the Hudson Valley Mall in Kingston.

Faith Community. The Benedictine team has a vibrant outreach program with religious organizations and a growing reputation for meeting community needs. As their reputation has grown, the breast health navigators are being invited to churches that serve specific populations in the community. They are collaborating on a screening day with the local chapter of Sisters Network, an African-American breast cancer survivor organization. Outreach is done through area African American churches. Benedictine’s breast health navigators plan to work with additional faith groups, including sisterhoods at the local synagogues. Ms. Schwartz, who is an interfaith minister, took the first step toward working with the faith community by speaking about breast health with members of a local interfaith council. The outreach team also provides information to nurses who work in Benedictine’s Parish Nurse Program, which currently serves ten parishes in the community, for distribution among the parishioners.

Migrant Workers. In partnership with the Ulster County Migrant Health Clinic, Benedictine is working to increase access to health care for migrant workers. Although this initiative had a slow start the first year (2002) given the short growing season, all partners are committed to conducting breast cancer outreach with this transient population. In preparation, Benedictine has obtained two Spanish language videos—*Breast Self Exam*, produced by Glaxo Wellcome and the Mayo Clinic’s *It’s Better to Prevent than Regret*—and continues to identify credible materials produced in Spanish. Benedictine plans to provide screenings and education at both the Ulster County Migrant Health Clinic and at the camps where workers stay. One lesson learned by this ambi-

tious team is that to accommodate this population, the team needs to consider mobile mammography or provision of services late in the day after the work has been done.

Prison Population. Because of the “buzz” the breast health team was creating in the community, the team gave a presentation to women in an alternative incarceration program. The team is currently in the planning stages for meetings with prison officials on how they can provide information and support to the incarcerated population of women and those who are part of the work release program.

A unique aspect of Benedictine’s outreach program is its holistic approach. The program does not focus solely on breast cancer prevention, screening, and education; rather, it combines information about cancer with information and education about healthy living and lifestyles that affect overall health. The breast health navigators practice what they preach. The *Celebrate Life!* newsletter lists educational forums, community outreach programs, and tips for healthy living, including healthy cooking and nutritionally balanced recipes.

Lessons Learned

A major ingredient in the success of Benedictine Hospital’s breast cancer community outreach program has been the breast health team and its community spirit, drive, and long-term commitment to individuals diagnosed with cancer, cancer survivors, their families, and friends. Along the way, the team has learned some insightful lessons.

Lesson One: First and foremost, reach out. Health care providers must go out into the community and bring the information and education to the sites where the community gathers—do not expect them to come to you, rather your role is to reach out.

Lesson Two: Cultivate relationships with community organizations—senior citizen groups, churches, civic organizations, schools—and be ready, willing, and able to network with every group. The breast health navigators noted that in the first six months they were at Benedictine, they never said “no” to an invitation to speak; this is paying off because more invitations are pouring in.

Lesson Three: Involve patients and their families. It is amazing how those who have survived cancer and their loved ones want to help others by offering nurturing and support. This is the secret of success for the Nurturing Neighborhood Network and the Companion/Advocate programs. Benedictine’s program succeeds because it offers “safe” places where people can let down their guard and be who they need to be, with the knowledge that they have understanding and acceptance.

Lesson Four: Understand the different cultures in the community and be sensitive to their needs. Benedictine team members got quite an education about migrant workers as they developed their outreach strategy for this group. They learned about the differences between packing and picking seasons, the hours and lifestyle of the workers, and the fact that many of the Hispanic women are extremely modest and often too tired at the end of the day to participate in screenings or be a part of educational activities. Thus, the navigators have to be creative in identifying methods for educating and screening this at-risk population.

Next Steps

Benedictine Hospital has a strong tradition and history of cancer care support, but the work is far from over. In many respects, the work is just beginning.

The Benedictine breast health navigators plan to continue their work with the migrant worker population, applying lessons learned this year to effectively provide education and services in the upcoming year. Further collaboration with the faith community and other local organizations also remains on the agenda.

One population the breast health team plans to focus on in the coming year is women with disabilities. Plans for this population include addressing barriers to transportation to support women with disabilities and eliminate the obstacles they face in obtaining preventive and screening services.

As a part of its mission to care for others, the Benedictine team is committed to actively identifying those who need support, comfort, and services, and pursuing innovative ways to serve these people. With the help and collaboration of the breast health navigators and the advocates/companions, one key objective is making sure that women have the assistance they need at doctor appointments and have access to information that helps them make informed decisions.

While Benedictine Hospital has a strong focus on serving its community, the breast health team is also actively engaged in the broader community. As a member of the HANYS BCDP™ Advisory Board, Benedictine will work with other hospitals around the state on important projects including physician-patient communications and resource kits for health care professionals and patients.

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