A Community Approach to Addressing Excess Breast and Cervical Cancer Mortality Among Women of African Descent in Boston

SYNOPSIS

In 2000, the REACH Boston 2010 Breast and Cervical Cancer Coalition conducted a community needs assessment and found several factors that may have contributed to disproportionately high breast and cervical cancer mortality among black women: (a) Focus group participants reported that many women in their communities had limited awareness about risk factors for cancer as well as about screening. (b) Black women experienced barriers to care related to the cultural competence of providers and of institutions. (c) Black women were not receiving adequate follow-up for abnormal mammograms and Pap smears. The Coalition’s Community Action Plan to address disparities includes a model primary care service for black women; scholarships to increase the number of black mammogram technologists; primary care provider and radiology technologist training about disparities and cultural competence; and education to increase awareness among black women and to increase leadership and advocacy skills.
Black women in the U.S. have excess mortality from breast and cervical cancer, compared with white women. For 1996–1998, the age-adjusted breast cancer death rate among black women in the U.S. was 26.2/100,000, compared with 19.0/100,000 for white women. For 1990–1994, the age-adjusted cervical cancer death rates were 5.9/100,000 for black women and 2.4/100,000 for white women. Studies comparing rates of mammography screening and breast cancer mortality for black and white women in the early 1990s determined that less than 15% of the variance could be attributed to screening. In 1998, the mortality rate from breast cancer was 40% higher among black women in Boston than among white women (Unpublished data, Boston resident deaths, Massachusetts Department of Public Health, analyzed by the Office of Research, Health Assessment and Data Systems, Boston Public Health Commission). For the time period 1995–1997, three times as many black women died from cervical cancer as white women. In Massachusetts, black women reported higher rates of breast and cervical cancer screening than white women on the Massachusetts Behavioral Risk Factor Surveillance Survey (BRFSS) (Unpublished 1992–1998 BRFSS data, Massachusetts Department of Public Health, analyzed by the Office of Research, Health Assessment and Data Systems, Boston Public Health Commission). The disparity in breast and cervical cancer deaths, therefore, does not appear to be solely attributed to lack of screening.

Several factors have been proposed to account for the disproportionately high rates of breast cancer deaths among black women. For example, McCarthy et al. reported that older black women have less regular mammography screening than older white women. Factors that may contribute to higher death rates among black women are delayed diagnosis, differences in tumor biology, confounding comorbid and socioeconomic conditions, and personal beliefs about cancer and mammography among black women. Recent data suggest that black women have a higher incidence of and more aggressive breast cancers before the age of 40 than white women in the same age range.

Cervical cancer disparities have been attributed to multiple factors. The lack of follow-up of abnormal Pap smears due to women’s fear of cancer, concern for reproductive function, and fear of pain; logistical barriers (transportation, child care); and lack of understanding of the implications of abnormal results are among the reasons cited for higher mortality from cervical cancer among black women than among white women.

Addressing high rates of breast and cervical cancer mortality among black women in Boston requires an understanding of the unique factors affecting Boston’s black community as well as the institutions and systems in Boston. Racial and Ethnic Approaches to Community Health (REACH) 2010 is an initiative of the Centers for Disease Control and Prevention (CDC) aimed at eliminating disparities in health status between the white population and black, Latino, Asian, and Pacific Islander Americans and American Indians/Alaska Natives in cancer, heart disease, infant mortality, HIV/AIDS, vaccinations, and diabetes. The goal of this initiative is to support community coalitions in designing, implementing, and evaluating community-driven strategies to eliminate health disparities. In 1999, a coalition of community activists, public health officials, academicians, and others formed the REACH Boston 2010 Breast and Cervical Cancer Coalition to address the disproportionate rates of breast and cervical cancer deaths for women of African descent in Boston. The Boston Public Health Commission is the convening agency and was awarded a 12-month grant to support planning and development of a Community Action Plan to address breast and cervical cancer disparities. We report here on the outcomes of the planning year and on the development of the community-driven Community Action Plan.

FORMING A COALITION

Understanding the most appropriate ways to address racial/ethnic disparities in breast and cervical cancer death rates requires an understanding of factors that contribute to health disparities, including health system factors, health care policies and procedures, personal factors among women of color, provider factors and provider-patient interactions, social factors in the community, and other issues that go beyond mammography and Pap smear screening rates. To ensure that approaches to addressing breast and cervical cancer mortality reflected the realities of women from Boston’s diverse black community, we developed a process to ensure involvement of a broad representation of community members, ranging from the women themselves to academic researchers.

In 1999, the Boston Public Health Commission, the health department of the city of Boston, convened key stakeholders to discuss their perceptions of the root causes of disparities in breast and cervical cancer mortality and to create a coalition representative of the diversity of the community. The initial meeting attendees represented members of a community coalition addressing disproportionate high rates of infant mortality in Boston’s black community, academic researchers, public health workers, local and state pub-
lic health officials, community health workers, women’s advocates, cancer advocates, and social service providers. The community coalition addressing disparities in infant mortality was invited as a key stakeholder for several reasons. First, its members recognized that attention to a broad range of women’s health issues was required to address persistent disparities in infant mortality and thus did not limit their attention to pregnant women. Second, the women participating in the infant mortality coalition overlapped with women who might be targeted for outreach related to cervical cancer, black women 18 to 45 years old. Finally, to be respectful of community women, the conveners believed that it was important to build on an already established coalition, recognizing its members’ time and commitment. It is unrealistic to build separate coalitions for every health issue arising in the city.

To facilitate community members’ participation in the Coalition, women representing the diversity of Boston’s black community (including African American, Haitian American, Caribbean American, and African immigrant women) were identified and asked to serve as Cluster Leaders. Cluster Leaders are women from the community who agree to work a few hours a week reaching out to other black women in their neighborhoods, churches, and other community settings to educate them about disparities, to ask women their opinions about factors that contribute to breast and cervical cancer disparities, and to bring them into the Coalition as cluster members. Cluster Leaders participated in a leadership development training that focused on: education about breast and cervical cancer, leadership, outreach, community organizing, self-help approaches, and public policy. They also attend monthly Coalition Steering Committee meetings and report on what they have learned from their activities in the community. Cluster Leaders organize cluster meetings and encourage cluster members to bring others in to widen the circle of women involved in learning about breast and cervical cancer.

Early on, the Coalition developed and adopted a set of organizational principles designed to ensure a balance of power between the community members and institutional representatives (Figure 1). Coalition members, including institutional representatives, participated in several trainings on Coalition development, breast and cervical cancer risk factors and screening recommendations, proven strategies for increasing

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**Figure 1. REACH Boston 2010 Breast and Cervical Coalition: Organizational Principles**

The Coalition will be governed by a steering committee, which is open to the following affiliated members:

- one representative from each of the original grant partner organizations;
- one representative from any interested organization/institution;
- Cluster leaders and Cluster members.

**Principles of Participation**

1. Steering committee members should be committed to the project and able to participate fully in the committee activities. Each Coalition steering committee member must sign (on behalf of his/her institution/organization) an affiliation agreement and agree to attend all member trainings.

2. There will be strong representation on the steering committee from members of the grant target population who are Boston community residents. Each cluster will have a minimum of three representatives on the steering committee, the cluster leader along with two cluster members. Representation from the cluster can be increased or decreased to promote equal representation of community residents and institutional representatives on the steering committee.

3. Decision-making will be by consensus as much as possible with a call for a vote only when the co-chairs have determined that consensus cannot be reached. When voting becomes necessary, each organization will have one vote on the steering committee. Each cluster representative will have one vote, with a maximum of three votes per cluster. A 2/3 majority is needed to carry a resolution.

**Organizational Structure**

1. Steering committee meetings will be held monthly on the first Monday at 6:00 p.m., unless otherwise stated.

2. Subcommittees can be formed at the request of Coalition steering committee members and/or staff to undertake particular projects, tasks, or initiatives with a report back to the steering committee.

3. The steering committee will appoint two co-chairs, one of whom must be a member of the target community. Each co-chair will serve for six months on a staggered rotation of three months so that both co-chairs do not leave at the same time. Appointment of the chair will be determined by the steering committee.
mammogram and Pap smear screening rates in black women, and cultural competence and ways of understanding and addressing racism. Results of a needs assessment and community mapping were shared with the Coalition members on an ongoing basis over the course of the first 10 months of the planning year. Coalition members participated in trainings on how to develop a Community Action Plan and a budget for the Plan; these trainings were based on the model described by Fawcett et al.10

**DOCUMENTING THE EXTENT OF DISPARITIES**

The REACH Boston 2010 Coalition includes institutions and individuals with different strengths, e.g., community members with knowledge about key stakeholders and change agents, public health officials with access to population-level data and experience with community health improvement initiatives, and academic institutions with expertise in research and evaluation. These Coalition members gathered both quantitative and qualitative data to understand the extent of disparities and to investigate factors contributing to disparities. Data describing the extent of disparities were collected from public health sources including the Massachusetts Department of Public Health death files and BRFSS results. Data relating to mammography screening among Haitian immigrant women were shared from a study already underway at the Haitian Health Institute at Boston Medical Center. Information about follow-up for abnormal breast exams and mammograms and for abnormal Pap smears was collected retrospectively by reviewing an administrative database from the safety net hospital in Boston.

**Breast cancer screening**

According to BRFSS data for 1995–1997, analyzed by the Office of Research, Health Assessment and Data Systems of the Boston Public Health Commission, 93.8% of non-Hispanic black women in Boston reported ever having mammogram, compared with 87.4% of non-Hispanic white women. However, only 77% of non-Hispanic black women and 70% of non-Hispanic white women reported having had a mammogram within the last two years. Data gathered through an oversampling of Boston residents for the 1999 BRFSS indicated that black and white non-Hispanic women in Boston had similar overall rates of screening for breast and cervical cancer. In a cross-sectional survey of women 40 years of age or older, randomly selected from a Boston neighborhood with a high concentration of Haitian American women, data for 331 women indicated that African American, Haitian American, Caribbean American, and Latina women all had similar rates of mammogram screening and their screening rates were lower than that of white women in the area. Longer time in the U.S. was associated with increased likelihood of screening among immigrant women. Twenty-three percent of respondents identifying as African American (without specifying a birthplace) had never had a mammogram, 3.7 times the rate (6.2%) for white women ($p=0.02$).

**Breast cancer mortality**

For 1995–1997, the age-adjusted breast cancer mortality rate for non-Hispanic black women in the city of Boston was 23.7/100,000, compared with 21.0/100,000 for non-Hispanic white women, according to death certificate data from the Massachusetts Department of Public Health analyzed by the Office of Research, Health Assessment and Data Systems of the Boston Public Health Commission. For 1998, the rate was 24.9/100,000 for black women and 17.8/100,000 for white women. The differences in breast cancer death rates vary by age, with the greatest disparities found among premenopausal and very old women (Figure 2). The Figure shows that younger black women (ages 35–44 and 45–54) have higher death rates than white women of the same ages, while the rates are similar for women ages 55–64, and white women ages 65–74 have higher rates than black women.

**Cervical cancer screening and mortality**

According to BRFSS data for the time period 1995–1997, 92.6% of non-Hispanic black women in Boston reported ever having a Pap smear, compared with 86.8% of non-Hispanic white women. However, only 81.8% of non-Hispanic black women and 73.3% of non-Hispanic white women reported having had a Pap smear within the last two years. For the time period 1995–1997, the age-adjusted cervical cancer mortality rate for non-Hispanic black women in Boston was 6.4/100,000, compared with 2.2/100,000 for non-Hispanic white women.

**WHAT ACCOUNTS FOR DISPARITIES IN BREAST AND CERVICAL CANCER MORTALITY?**

Disparities in health can be attributed to several factors. The REACH Boston 2010 team investigated these potential factors at several different levels by conducting focus groups with black women, surveying institutions and providers, and reviewing medical records related to breast and cervical cancer screening and follow-up.
Listening to the community

Focus groups are reliable for conducting needs assessment and exploring beliefs about and understanding of complicated health issues such as disparities in health. Focus groups allow for a fresh perspective on problems that have previously been explored. We wanted to avoid developing a Community Action Plan based on preconceived ideas about the causes of elevated breast and cervical cancer mortality among black women in Boston. Focus groups were conducted with 48 women ages 19–73 years of different ethnic backgrounds from Boston’s black community, including African American women and women of Caribbean, Haitian, and Somali descent. The focus groups explored women’s perceptions of why breast and cervical cancer death rates were higher among black women than among white women; their understanding of why screening exams are performed; risk factors for breast and cervical cancers; and barriers to care. Several themes emerged from the focus groups. First, black women generally do not talk about breast cancer and risks for breast cancer among family and friends. The opinion that breast cancer is a white woman’s disease was common among focus group participants. Women held many inaccurate assumptions about risk factors for breast and cervical cancer, though most knew that cervical cancer risk is related to the number of sexual partners. Mammography was viewed as helpful but painful or inconvenient.

The women were not familiar with the term “cervical cancer” because they did not understand the word “cervix” as the opening to the womb. They were unaware of the relationship between a Pap smear and screening for cervical cancer. The women understood that Pap smear screening was a part of a check-up but were unsure of its purpose. Universally, women were also unfamiliar with common terms to describe abnormal Pap smear results and did not understand the implications of abnormal results.

Haitian and Somali women experienced language barriers. Somali women also raised concerns related to Pap smear screening in women who had undergone female genital cutting. They described conflicts between their belief systems (destiny determined by God) and the rational for preventive screening. The focus group participants were also concerned that black women held many myths about cancer in general and breast cancer specifically. These myths included be-
lies about the relationship between breast cancer and breast feeding, wearing bras, and trauma to the breast.

Health system barriers

Breast cancer screening. The focus groups revealed several health system barriers for black women. Among these were the lack of diverse staff and logistical barriers in terms of hours and days of operation of mammogram units. The women also described barriers related to their interpersonal relations with providers, including providers who do not do screening breast exams or order mammograms and providers who lack cultural competency. Mistrust of medical providers due to fear of being misdiagnosed or improperly treated was also a major barrier. Focus group participants also described poor experiences with mammography technologists who did not understand the breadth of cultural issues that interfered with black women’s ability to understand what to expect when undergoing mammography—such as beliefs about causes of cancer and concern about the cancer being universally fatal—and lacked respect for their desire to be clothed.

Focus group participants identified waiting times for mammogram appointments as a problem. A survey of mammography units in the city of Boston conducted as part of the needs assessment revealed that waiting times for a mammogram appointment ranged from two weeks to four months, with most institutions reporting a wait of more than one month. A mammography van did not make up for the lack of access to timely appointments. Frequently the van could not accommodate requests from community health centers and other community organizations to appear in the community due to a lack of mammography technologists.

A retrospective review of follow-up for abnormal breast cancer screening among women referred to the safety net hospital by physicians at the hospital and by 12 neighborhood health centers indicated that 44% of women younger than 40 and 25% of women 40 and older did not keep follow-up appointments. Women with public or no insurance and those referred by neighborhood health centers were least likely to follow-up.

Cervical cancer screening. A retrospective cohort study of women with abnormal Pap smears was conducted as part of the needs assessment. The cohort was a group of predominantly black women, ≥18 years of age, most without private insurance, who sought care at one of seven neighborhood health centers or at the city’s major safety net hospital. The results of a medical records review revealed that follow-up rates for abnormal Pap smear cytology were low. Only 53% of women had follow-up for dysplasia within four months, and 56% had follow-up for atypia within seven months.

Only 45% of women younger than 30 had follow-up by seven months.

Institutional survey. We conducted a survey of all institutions in Boston offering mammograms and of hospital-based clinics, community health centers, and community-based medical groups providing primary care to women, gynecologic care, and thus follow-up treatment for women with abnormal Pap smears. The results of the institutional surveys reveal several factors that may contribute to poor follow-up rates among black women. Only half of the responding mammography units tracked women who miss routine appointments or follow-up appointments for abnormal results. Most institutions tracked abnormal Pap smear results. Providers cited a need for more Saturday and evening appointments, day care and transportation, and more racially and linguistically diverse provider staff to enhance their ability to provide better care to black women. The racial identity of the technical and professional staff was not representative of black women. Providers also indicated that providing resources to fund outreach workers would help to bring women in for follow-up appointments.

Existing programs

The Coalition identified several related programs addressing breast and cervical cancer screening. These ranged from an in-home education and outreach program to encourage women to get regular mammograms to the Massachusetts Department of Public Health’s CDC-funded screening program, which provides free mammograms and Pap smears to income-eligible, uninsured women. Women identified with breast or cervical cancer by this program do not have access to any specific resources to treat their cancer, as Massachusetts does not participate in optional Medicaid funding for this purpose.

THE COMMUNITY ACTION PLAN

The Coalition developed the Community Action Plan after learning about existing disparities and the results of the assessment of possible factors contributing to disparities. The Coalition agreed upon the following mission statement:

The mission of Boston’s REACH 2010 Breast and Cervical Cancer Coalition is to eliminate racial and ethnic disparities in breast and cervical cancer by creating, with the community, a culturally competent system which promotes education, prevention, screening, treatment, and access to care for black women and women of African descent in Boston.
Coalition members from the community expressed a strong intention not to “create only another program to educate black women about how they should be taking care of themselves” but to also address “the need to change the system.” The Community Action Plan was designed with this principle at the forefront, and the interventions address the need for both systemic changes and changes in personal knowledge and behavior. The Plan focuses on women of African descent who, because of barriers in the system or in their life situations, are inadequately connected to the health care system and/or are especially hard to reach with conventional methods. The Community Action Plan employs an integrated set of strategies to increase the percentage of women who get regular screening; to improve follow-up to screening; to improve the health care infrastructure; to change policies and procedures; to increase the cultural competence of providers; to make services more accessible; and to empower women to seek out and advocate for their own health care. Interventions to achieve these goals move through the five stages of a framework for promoting health—from capacity building through targeted action, community/system change, and widespread risk behavior change, leading to the elimination of racial disparities in breast and cervical cancer mortality (see Figure 3).

COMMUNITY ACTION PLAN STRATEGIES

Inreach
These interventions focus on connecting women to the health care system and improving the health care system’s infrastructure to better serve women.

Women’s Health Demonstration Project. The Coalition adapted an existing model system of comprehensive care for women at six primary care settings serving significant numbers of black women. The model was already under development by a group working on reducing infant mortality in Boston. The model reconfigures primary care services for women, empowering women to take charge of their health by expanding the primary care team to include case managers/outreach educators and instituting a culturally appropriate needs assessment. This standardized assessment tool screens women for medical and social risks and provides women and their physicians or nurses with feedback about important medical and social problems and potential strategies for addressing them. Case managers are available to connect women with resources, including facilitating follow-up for abnormal Pap smears and mammograms.

The Project’s goals are to identify black women and connect them with screening and treatment services; to support women through follow-up and treatment; to address breast and cervical cancer in the context of women’s health; and to improve patient satisfaction with the quality and cultural competence of care. The six facilities also agreed to develop systems for tracking women who do not get regular Pap smears and mammograms and who do not follow up on abnormal results. The clinical sites also serve as settings in which to assess educational materials specifically designed for women of African descent. Representatives from each clinical site and the case managers hired for the REACH project joined the REACH Boston 2010 Coalition.

Provider training. To increase the number of culturally competent providers and the percent of women reporting culturally competent care, the Community Action Plan includes strategies to develop curricula and provide training for women on disparities in health and cultural competence training for primary care providers—including physicians, physician assistants, and nurse practitioners—and for radiology technologists. These trainings address the impact of race and ethnicity on access to care, especially as it relates to breast and cervical cancer. Also addressed are cross-cultural and cross-racial communication skills; strategies for engaging women in activities to prevent or diagnose breast and cervical cancer at an early stage; screening, diagnosis and treatment options; risk assessment and counseling; cultural issues (for example, the influence of religion on attitudes about screening; female genital cutting; and differences in concepts of time); strategies for communicating suspicious or abnormal findings; and strategies for making referrals for follow-up and/or special procedures. The training program for primary care providers is a train-the-trainer model. This model identifies a core group of providers at each of the six demonstration sites who return to their sites and deliver the training so that each site develops and maintains the ability to train its own staff. The program also provides low-cost training to meet annual continuing education requirements of mammogram radiology technologists, and seeks to train more than 50% of technologists practicing in Boston over four years.

Program to increase the supply of radiology technologists trained in mammography. This intervention includes a program to recruit and support prospective mammography radiology technologists, especially black women, who agree to work in Boston for at least two years after graduation. The main elements of the intervention include a partnership with a radiology tech-
nologist degree program at a local community college; identification and recruitment of potential black enrollees (including recruitment by Cluster Leaders); identification of barriers to enrollment in and completion of the degree program; and development of methods to reduce barriers, including scholarship resources and tutoring services. The radiology technologist students are also invited to join the Coalition.

Outreach
The Cluster Leaders, representing groups within the target population (e.g. Somali immigrant women,
members of faith communities) reach out to specific populations and include them in Coalition activities. Cluster Leaders coordinate member participation in trainings and education and outreach activities. Immigrants, adolescent girls (with a focus on developing positive lifetime behaviors), and members of faith communities (the main place of support for black women in Boston) are specific targets of the outreach. Outreach activities to immigrants are conducted at sites where classes for English as a second language are held, ethnic food stores, and cultural events. Outreach to adolescent girls takes place at school-based health centers, girls clubs, and community centers and uses a peer education model. Outreach to faith organizations takes place through a program of mini-grants.

**Public education.** The Community Action Plan includes a multi-phase public education campaign to increase awareness of disparities and risk factors for breast and cervical cancer mortality and to empower black women and their families to seek out, advocate for, and evaluate their own health care. The strategy includes development and/or testing of materials and messages to educate black women about breast and cervical cancer risks, about the importance of screening, and about the importance of following up abnormal results. The campaign targets women who are not well connected to health services, black immigrant women, and black adolescent girls. The campaign will be conducted in languages appropriate to the target population, including but not limited to Haitian Creole, Spanish, and Somali. Cluster Leaders, peer leaders, and other members of the Coalition speak at meetings of community groups to share information with their members about breast and cervical cancer screening.

**Policies and procedures.** The Coalition identified policies and procedures—for example, limited interpreter accessibility and lack of reimbursement for outreach workers and case managers—as barriers to comprehensive approaches to eliminating disparities in breast and cervical cancer. The Coalition created a policy subcommittee to identify potential changes in at least two city, state, or private sector policies or procedures that could have a significant impact on eliminating racial disparities. Cluster Leaders and Coalition members will participate in a leadership and advocacy training program and develop mechanisms for informing community and other key players about policy priorities and how to take action resulting in change.

**Coalition and partnership development**

Continued development and growth of the Coalition is key to its success. One mechanism for ensuring that community members will have meaningful representation on the Coalition is to recruit women from the clusters as Coalition members. The Coalition has identified an independent evaluator to provide candid, confidential perspectives to assist the membership and leadership to develop best practices regarding Coalition growth, maintenance, and productivity as well as to sustain cooperation toward achieving the Coalition’s goals and objectives. In addition, the Coalition will develop and implement a Leadership Development Institute for at least 25 community members per year to empower them to seek out, advocate for, and evaluate their own health care and the care of their family members. They will also serve as active participants in the Coalition’s policy initiatives. Training topics will include Coalition development, anti-racism, wellness, community organizing, and policy development.

**SUMMARY**

The REACH Boston 2010 Breast and Cervical Cancer Coalition is a strong partnership among women from Boston’s black community, community-based programs, community activists, community health centers, public health agencies, and academic health centers. A Steering Committee with community leadership provides oversight for the Coalition’s activities. A needs assessment identified multiple factors that may contribute to the well-documented disparities in breast and cervical cancer deaths in Boston. Addressing disparities requires interventions at multiple levels.

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**REFERENCES**

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