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## Cancer Health Disparities: What We Have Done

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### KEY INDEXING TERMS

Health disparities; Cancer prevention; African American; Breast cancer; Cervical cancer; Rural medicine

It is well established that disparities in health care exist and that they exist for many disease processes.<sup>1</sup> Disparities in cancer outcomes are a significant contributor to this problem.<sup>1–5</sup> Disparities in cancer outcomes and treatment have been documented in ethnic minorities and the poor; in addition, inhabitants of rural areas experience healthcare disparities due to compromised access.<sup>5,6</sup> This paper will focus on practical solutions to the problem of cancer health disparities among ethnic minorities in both rural and urban areas, developed through 3 programs of the University of Alabama at Birmingham: the Deep South Network for Cancer Control (DSN), the Racial and Ethnic Approaches to Community Health 2010 (REACH 2010), and the Community Health Advisors in Action Program (CHAAP).

DSN was established to improve the awareness regarding cancer risks and preventive strategies, enhance the participation of African Americans and other special populations in clinical trials, and develop novel, community-based strategies to reduce cancer disparities.<sup>7–9</sup> REACH 2010 was developed to build coalitions and mobilize resources within the community to address breast and cervical cancer issues. CHAAP was developed to help patients navigate the health-care system and receive appropriate high-quality care. While REACH 2010 and CHAAP were implemented only in Alabama, DSN was implemented both in Alabama and Mississippi.

The overarching goal of all 3 programs was to reduce cancer health disparities by increasing cancer awareness and improving the access to state-of-the-art cancer care for medically underserved, primarily African American, populations.

### Cancer Health Disparities

Disparities in cancer are a major problem among racial and ethnic minorities in America. African Americans face a considerable disparity with regard to cancer incidence and mortality. Compared with white men, African American men have a 25% higher incidence and 43% higher mortality rate for all cancer sites combined.<sup>10,11</sup> African American women have lower incidence rates than white women for all cancer sites combined, yet they have a 20% higher mortality rate.<sup>10,11</sup> For many cancer sites, incidence and mortality rates are consistently higher in African American than in white women, except for breast cancer (incidence) and lung cancer (mortality). However, the breast cancer mortality rate is 28% higher among African American women compared with white women.<sup>12</sup> In addition, death

rates from cervical cancer among African American women are more than twice those of whites.<sup>10,11</sup>

A poorer probability of survival once cancer is diagnosed contributes to the higher mortality rates among African Americans. For most of the common cancers, African Americans are less likely than whites to be diagnosed with localized cancer—when the disease may be more easily and successfully treated—and more likely to be diagnosed with cancer that has spread regionally or to distant organs.<sup>10</sup> Further, for nearly every cancer site, African Americans have lower 5-year relative survival rates than whites at each stage of diagnosis, which suggests the possible influence of disparities in access and receipt of high-quality health care and differences in comorbid conditions.<sup>13</sup>

The reasons for such cancer disparities are several. There are documented disparities in knowledge and awareness of the disease.<sup>14,15</sup> In addition, there are documented disparities in access to health care, resulting in differential treatment of the disease.<sup>4,14,15</sup> Moreover, where cancer treatment is available, there is evidence of disparities in the quality of treatment.<sup>4,14</sup> Recent findings suggest that African Americans and whites have similar disease outcomes when they receive similar cancer treatment and medical care.<sup>4</sup>

## Theoretical Framework

### The Community Health Advisor Model

The programs described in this article are founded on the Community Health Advisor (CHA) model as incorporated by the CHA Network<sup>16</sup> established in 1993 by the Center for Sustainable Health Outreach at the University of Southern Mississippi. The CHA model is based on the Paulo Friere's Empowerment Theory,<sup>17,18</sup> which holds that the communities will address social-change goals brought from the outside only if they are empowered to address their own concerns and goals. Once a social-change goal is considered desirable by the community, partnerships that include grassroots representatives increase the likelihood of connecting to hard-to-reach, at-risk individuals.

The CHA model builds on the premise that in every community there are people to whom others go to for advice, assistance, and action; they are commonly known as “natural helpers.”<sup>19</sup> The model seeks to identify, recruit, and train these natural helpers (CHAs) to improve their knowledge of health issues, enhance their innate abilities, augment their problem-solving skills, and assist them in developing actions to address community health issues. The model involves building linkages between community members, local service providers, and formal community leaders.<sup>16</sup>

CHAs are local residents who share cultural or ethnic characteristics with the population to be served and provide support and health education to family, friends, neighbors, and other community members. In our programs, some CHAs were trained to promote cancer awareness, recruit for clinical trials, and assist with the community-based research, and others to serve as health-system referrers, patient navigators, and case managers.

### Building Community Capacity

Three behavioral theories—the Empowerment Theory,<sup>17,18</sup> the Community Development Theory,<sup>20</sup> and the Diffusion Theory<sup>21</sup>—constituted the basis of our efforts to build community capacity. In addition, the principles of community-based participatory research,<sup>22</sup> a partnership approach that equitably involves all parties in the research process, guided our activities. A major goal of our programs was to create community capacity so that cancer awareness and cancer control could activities be advanced among African Americans in underserved areas. This was done through coalition building and creating

infrastructure on both state and community levels. Additionally, the capacity was created on the individual level as well, by recruiting and training CHAs to work within their communities.

## Methodology

### Geographical Coverage Area

The programs described in this paper were developed in the Black Belt of Alabama and the Delta of Mississippi, which have a disproportionately large population of African Americans and socioeconomically disadvantaged people. The Black Belt refers to an area stretching across Alabama's south-central counties and named for both the dark color of its fertile soil and the extremes of poverty and deprivation among its African American population. This area, among the nation's poorest, has been termed "America's Third World."<sup>23</sup> The Delta of Mississippi refers to a very flat area of northwest Mississippi that borders the Mississippi River and has an economy predominantly based on agriculture.

The Alabama Black Belt and the Mississippi Delta exhibit some of the most concentrated areas of racial/ethnic disparities in the United States: per capita income is less than \$13,000, one-third of the residents live below the poverty line, and more than 60% of the population is African American.<sup>5</sup> This combination of economic and social challenges produces a powerful setting for the continuation and exacerbation of widely recognized health disparities. Table 1 demonstrates the prevalence of African American population and the substantial poverty in these areas.

The Delta and the Black Belt are both rural areas. To demonstrate that our programmatic activity could be applied to both rural and urban African American populations, we selected geographically defined urban areas in Birmingham (Jefferson County), Tuscaloosa, and Montgomery (Alabama) and Laurel/Hattiesburg (Mississippi), where we also implemented our programs.

### Targeted Cancers

Our choice to focus on breast and cervical cancer was based on 4 reasons: (1) the mortality for each of these cancers is substantially higher in the African American population compared with whites (34.4 versus 25.4 per 100,000 for breast cancer,<sup>24</sup> 5.1 versus 2.4 per 100,000 for cervical cancer<sup>25</sup>); (2) effective screening modalities exist for each cancer, with proven reduction in mortality when applied to populations; (3) screening for breast and cervical cancer is available in both Alabama and Mississippi, regardless of ability to pay, through the Centers for Disease Control (CDC)-funded Breast and Cervical Cancer Early Detection Program; and (4) Alabama and Mississippi have both passed the Breast and Cervical Cancer Treatment Act, which allows provision of treatment through Medicaid for cancers detected through the Breast and Cervical Cancer Early Detection Program.

### General Overview of Programs

The programs discussed in this paper have been described in detail elsewhere.<sup>7-9,26-29</sup> We provide a general overview of the programs.

**DSN**—DSN was established to improve awareness regarding cancer risks and preventive strategies, enhance participation of African Americans in clinical trials, and develop novel community-based strategies to reduce cancer disparities. The purpose of DSN is to eliminate the disparity in breast and cervical cancer between African Americans and whites in the Deep South (Alabama and Mississippi) through community-based participatory research, education, and training. The DSN builds upon community infrastructure, state partnerships,

and coalitions to develop, implement, and evaluate an intervention that is participatory and developed by the targeted communities to address breast and cervical cancer disparities. Funded by the National Cancer Institute, DSN is a collaborative effort between academic and community-based organizations. The University of Alabama at Birmingham, the University of Alabama, and the University of Southern Mississippi partnered with businesses and educational, faith-based, governmental, health-care, media, and nonprofit organizations in Mississippi and Alabama and worked with volunteer CHAs to promote cancer awareness, recruit for clinical trials, and assist with community-based research.

**REACH 2010**—Alabama REACH 2010, funded by CDC, was initiated to address racial and ethnic breast and cervical cancer health disparities. Based upon the ideal that building community capacity should lead to positive actions and ultimately result in behavior change, REACH 2010 has the mission to empower the community to eliminate breast and cervical cancer morbidity and mortality disparities between the white and African American women in 2 urban and 6 rural counties in Alabama. The program comprises a well-established coalition that consists of nonprofit organizations, health department, medical society, faith-based institutions, universities, health-care organizations, private foundations, and community volunteers functioning as core working group (CWG) members, who represent CHAs, health professionals, and members of the clergy/faith-based organizations. The CWG first assessed the breast and cervical screening behavior of women in their communities, then disseminated health messages and conducted activities to encourage and support women to obtain breast and cervical cancer screening.

**CHAAP**—CHAAP, funded by the Avon Foundation, was developed to help patients navigate the health-care system and receive appropriate high-quality care. The objective of CHAAP was to assess the feasibility of developing and implementing a community-based navigator program designed to increase access to care and appropriate medical follow-up for underserved, low-income women who present with an abnormal breast cancer screen or have a confirmed diagnosis of breast cancer. In an effort to connect the community with the health-care system, the CHAAP staff identified “natural helpers” in the community and recruited and trained them to serve as CHA navigators. Breast cancer patients were recruited or referred to CHAAP by various sources and triaged to the CHA navigators, who assisted them in addressing barriers to diagnostic follow-up and treatment by acting as health-system referrers, patient navigators, or case managers.

## Results

### DSN

Investigators united with national and state organizations in both Mississippi and Alabama and established statewide coalitions. In Mississippi, the DSN investigators partnered with the Mississippi State Department of Health and wrote a CDC-funded 5-year planning grant to develop the state’s first cancer plan. Moreover, the Mississippi Partnership for Comprehensive Cancer Control was established as a statewide coalition of organizations interested in reducing the burden of cancer in the state, with a DSN investigator as the first chair. In Alabama, the Alabama Partnership for Cancer Control in the Underserved was established as a nonprofit organization to build capacity for cancer control in the state.

A second tier of coalitions, coalitions on a community level, was developed by the CHAs within their communities. By partnering with other community groups interested in reducing health disparities, the CHAs disseminated their cancer-control messages more efficiently and on a larger scale than they would have by working independently. The community groups included local staff and volunteers from the American Cancer Society, health-care

providers and organizations, African American sororities and fraternities, faith-based organizations, small business owners, and the National Cancer Institute's Cancer Information Service. As a result of efforts of DSN staff and CHAs in 1 rural community in the Mississippi Delta, the Fannie Lou Hamer Cancer Foundation was established. (Ms. Hamer was a civil rights leader from the Mississippi Delta who fought for voting rights and died from breast cancer.) This is a significant reflection of the strong heritage and empowerment of African American CHAs in the Mississippi Delta.

The DSN recruited and trained 883 volunteer CHAs in Alabama and Mississippi to promote cancer awareness, recruit for clinical trials, and assist with community-based research. The mean age of the CHAs was 45 years, 97% of them were African American, 94% were women, 76% were high-school graduates or higher. From 2001 to 2004, CHAs organized and participated in 740 activities. They were involved in 176 health fairs and 72 church events and made 100 health presentations.

Additionally, CHAs assisted in recruitment to the National Cancer Institute-funded Prostate, Lung, Colon, and Ovarian Cancer Screening Trial at the University of Alabama at Birmingham. More than 1,000 African Americans were recruited to the trial in Alabama. CHAs are currently participating in recruitment to the National Lung Study Trial, retention of subjects in an industry-sponsored Human Papilloma Virus vaccine trial at the University of Alabama at Birmingham, and recruitment to the SELECT prostate cancer prevention trial in the Delta.

## **REACH 2010**

REACH 2010 established the Alabama Breast and Cervical Cancer Control Coalition with 19 coalition members across the state. This multidisciplinary, ethnically diverse coalition included 2 academic institutions, 3 state institutions, and a number of faith-based and community-based organizations. The coalition was successful in maintaining 95% of its members during the course of this 7-year effort.

The coalition identified individual, community-system, and health-care provider barriers to early detection and treatment of breast and cervical cancer and developed a community action plan to: (1) address barriers to participation in breast and cervical cancer screening on individual, system, and agents-of-change levels; (2) train volunteers as CHAs to implement the intervention; and (3) identify and train church and health-care representatives from each county to serve as advocates for the project and support the efforts of CHAs.

To complement the local, grassroots efforts of the CWG members and to further spread breast and cervical cancer awareness messages among the agents of change, the coalition awarded 45 mini-grants to nonprofit organizations interested in promoting the mission and goals of the REACH 2010. The REACH 2010 coalition enrolled 215 volunteers: 143 CHAs, 49 church representatives, and 23 health professionals; their mean age was 54 years; 96% of them were African American, 95% were women, and 60% were high-school graduates or higher. The CHAs identified 2,333 women eligible to participate in the breast and cervical cancer screening program, and 1,539 women were followed through the multiyear intervention.

## **CHAAP**

The CHAAP study established partnerships with 6 major health-care networks or treatment facilities in 4 targeted counties. Thirty-eight community volunteers were recruited and trained as CHA navigators. All volunteers were African American, 97% were women, mean age 45 years, and 65% had a high-school education or higher. One hundred forty-seven women diagnosed with breast cancer or positive mammogram screening results were

enrolled as patients. Of them, 65% had a confirmed diagnosis of breast cancer and 25% had abnormal mammograms; 92% were African American; 73% had annual income less than \$10,000; 32% were separated or divorced; 52% were unemployed; 22% had no insurance coverage at all, and 52% had Medicare or Medicaid.

The CHA navigators identified the following barriers faced by patients: 72% of patients required more information about breast cancer, 57% had financial needs, 67% needed emotional support, 61% asked for help with hospital navigation, 52% were in need of social support, 44% needed transportation to facilities, and 31% had barriers resulting from religious beliefs. Of a total 1,384 appointments, navigators were successful in helping patients overcome barriers and keep 1,286 of their appointments, resulting in a 93% compliance rate.

## Lessons Learned and Summary

The University of Alabama at Birmingham has taken an active role in reducing cancer health disparities in the Deep South by developing 3 programs that are similar yet different. The programs are similar in that they used the CHA model and built community capacity, but are unique in the method of accomplishing their goals. The CHA model, originally developed by the CHA Network to fight hunger and malnutrition, was effectively adapted to focus on a specific disease and serve as a framework for reducing health disparities in both rural and urban communities.<sup>28-30</sup> The CHA training curriculum developed for the CHA Network is nonprescriptive in that community members can choose the health information subjects that are of interest to them and develop health improvement actions appropriate for their community. This empowers community members, as they develop ownership of the problems and the solutions that will bring about community health improvement. By tailoring the original CHA Network curriculum to promote breast and cervical cancer control through trained CHAs in low-income communities, we were able to reach women who are hard to reach through traditional health-education methods.<sup>7</sup>

We used the adapted CHA model to develop a volunteer, grassroots community infrastructure of trained community persons to disseminate cancer awareness information and conduct community action planning for improved knowledge of community resources and better access to breast and cervical cancer screening and treatment. The DSN trained about 900 CHAs in Alabama and Mississippi in breast and cervical cancer awareness and message dissemination methods to permeate underserved communities in both states with their message. REACH 2010 also used the CHA model but within the frame of building and maintaining a multidisciplinary, multiethnic community-based coalition to disseminate cancer awareness messages and develop breast and cervical cancer interventions. The lessons learned from this collaborative venture were as follows: (1) there is no shortcut to coalition building and maintenance—both require time; (2) respect everyone and value their input; (3) be flexible and open to change; (4) listen and respond; and (5) know when to call in the experts.

CHAAP focused exclusively on patient navigation to increase access to diagnostic follow-up and treatment for underserved, low-income women who presented with an abnormal breast cancer screen or a confirmed diagnosis of breast cancer. The term “patient navigator” appeared in the medical literature around the mid-1990s, first in a study conducted by Freeman, Muth, and Kerner whose goal was to enhance access to tests and follow-up services among medically underserved populations. Typically, patient navigator programs in the United States utilize as navigators clinic-based professional or lay personnel inserted into a health-care setting.<sup>31</sup> These navigators are employed to assist patients who have contacted the health-care provider for recommended follow-up after a suspicious



mammogram or a breast cancer diagnosis. The navigators play a reactive role by troubleshooting a patient's problems as they arise.<sup>31</sup> In contrast, CHAAP utilized community-based volunteers who proactively recruited hard-to-reach patients and helped them overcome barriers to seeking medical care after a suspicious or positive mammogram.

Across the 3 programs, the motivation of volunteers to become CHAs was the genuine desire to help people in their community and get involved with health issues. By engaging such a large number of volunteer CHAs, we believe that we have made a significant impact on the disparity in knowledge regarding cancer and preventive strategies. All intervention counties saw an increase in mammography and Pap smear utilization among African American women, as well as an unprecedented rate of keeping up with recommended medical follow-up. These noteworthy increases show that community volunteers who are properly trained and supported are indeed capable of both influencing individual behaviors as well as changing community conditions to foster an environment that promotes and encourages participation in breast and cervical cancer screening and recommended medical follow-up.

In conclusion, we have demonstrated that community engagement on a volunteer basis is feasible and effective in addressing issues of disease awareness, health-care access, and quality of treatment. This approach was effective in rural areas, where access and quality of care are an issue. Local adoption of these programs should be effective in reducing disparities in cancer screenings and, hopefully, cancer deaths. Understanding the local cultural beliefs and attitudes is important, and the inclusion of volunteers from local communities helps address those concerns.

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**Table 1**

Select Demographic and Economic Characteristics of the Targeted Population

	<b>African American</b>	<b>Per capita Income</b>	<b>% in Poverty</b>
Alabama Black Belt	67%	\$12,692	32%
Mississippi Delta	60%	\$12,530	28%
U.S.	13%	\$21,587	13%

Source: U.S. Census Bureau, 2000.