Reducing Health Disparities: From Theory to Practice

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Introduction
This paper outlines an approach to race, racism, and their intersection with cancer and other health outcomes that share common risk factors with cancer. In 2003, it is estimated that 132,700 new cases of cancer will be diagnosed among African-Americans, and 63,100 deaths will be recorded (1). Cigarette smoking is more common among African-American men than among Caucasian men, although the reverse is true among women. Physical activity, clearly related to lower risk of colon and breast cancers (2), is less prevalent among African-Americans than among Caucasian adults (1). Obesity levels are associated with increased risk of a range of cancers and are also higher among African-Americans (3). Although screening tests can detect cancers at early stages, African-Americans are less likely than Caucasians to report screening for colorectal cancer, although they reported comparable rates of screening for breast, cervix, and prostate cancers in 2000 and 2001 (1).

Herein we describe an underserved community and our work on coalition building to address disease risk, based on historic social transformation models. We established a Boston-based community coalition, COHS,2 using the strategies from successful social transformation models to improve the health outcomes of a specific ethnic- and geographically defined population. The paper also describes race, racism, and health disparities from an historical perspective, with emphasis on cancer disparities and lessons learned.

Racial and Ethnic Disparities in Cancer. Several manuscripts in this symposium have highlighted significant disparities in cancer morbidity and mortality rates of cancer by race (1). In one major review of the literature, Bach et al. (4) questioned whether existing data challenge or support the theory that blacks have poorer cancer survival rates than whites because of biological factors. Articles included in their review were required to: (a) include data for at least 10 black and 10 white patients with cancer; (b) state the clinician measures used to minimize the number of patients lost to follow-up; (c) specify the cohort ascertainment method; (d) summarize survival for both blacks and whites using actuarial measures; (e) present outcomes within stage, adjusted for stage, or outcomes based on cohorts with balanced-stage distributions; and (i) specify that blacks and whites in the study received similar treatment. They found that in 54 articles, 89 distinct cohorts were analyzed. The cohorts reported on a total of 32,004 black patients and 189,877 white patients with 14 various cancer types. The overall survival rates and HRs were calculated, and also adjusted for deaths because of noncancer factors. This adjustment determined the cancer-specific survival rates and cancer-specific HRs. Across the 89 cohorts, blacks were at a 16% increase risk of death because of cancer (HR, 1.16; 95% confidence interval, 1.12–1.20). Of the 14 cancer sites reported in the study, the cancer mortality rates of blacks were significantly higher for breast cancer, uterine cancer, and bladder cancer. After adjustment for underlying causes of death, the excess mortality rate among blacks was 7% (cancer-specific HR, 1.07; 95% confidence interval, 1.02–1.13). The gap in cancer survival rates between blacks and whites with similar stages of cancer and similar treatment was not significant after accounting for death rates. Thus, the authors concluded that the differences in survival are not because of biological factors, but more likely caused by other factors such as differences in treatment, stage of disease at the point of diagnosis, and the influence of other illnesses. Consistent with this review, data from the United States Surveillance, Epidemiology, and End Results program from 1973 to 1999 indicate that for total cancer incidence, and for incidence of lung, colon and rectum, breast, uterus, and prostate cancers, African-Americans have more advanced disease at diagnosis than do Caucasians (5).

In another major study, the authors examined differences in disease stage at the time of diagnosis, and the survival rate for Medicare cancer patients and the non-Medicare cancer patients (6). Three Michigan statewide databases (the Cancer Registry, Medicaid enrollment files, and Death Certificate Registry) were used to analyze the relationship among age, race, and low income, and cancer diagnosis and survival. The study focused on cervix, lung, prostate, colon, and female breast cancer. Differences in incidence, disease stage at time of diagnosis, and survival rates were analyzed for younger and older men and women who were either insured by Medicaid or not. Medicaid patients had a higher incidence rate of cancer, specifically colon and lung cancer among women and lung cancer among men. Medicaid-insured persons had a greater likelihood of late-stage diagnosis and death from colon, breast, cervix, lung, and prostate cancer. African-American women with breast cancer have a greater risk of late-stage diagnosis and death from breast, colon cancer, and prostate cancer. African-American women with breast cancer have a greater risk of late-stage diagnosis compared with Caucasian women, independent of Medicaid status. The authors concluded that low-income persons are being diagnosed with cancer during the late stages of the disease. The younger Medicaid population has a greater risk compared with the non-Medicaid population. Overall, low-income African-Americans have a higher proportion of the burden, with younger patients being diagnosed with later stages of breast and colon cancer among the younger population, and cervical cancer among the elderly.

Roxbury. Our target population is African-American women, men, and children living in Roxbury, a vibrant and diverse urban neighborhood of Boston. The neighborhood shares one border with world-renowned health care institutions and re-
sources, and another border with Boston’s Zoo and Franklin Park Golf Course. Despite some regional advantages, a rich history and geographic beauty, Roxbury is one of the poorest neighborhoods in Boston, with many of the worst levels for health indicators and other problems. Roughly 54,000 of the 650,000 people in Boston live in Roxbury. All except one of 20 census tracts in Roxbury were designated Health Professional Shortage Areas by the HRSA. In the 2000 census, 51.5% of the residents identified themselves as Black (non-Hispanic), 23.5% as Hispanic (of any race), 15% as Caucasian (non-Hispanic), and 4.5% as Asian. Another 3% of Roxbury residents identified themselves as multiracial, with Black (non-Hispanic) as one of their races. Roxbury has the youngest, poorest, least educated, and least employed population of all of the Boston neighborhoods. Twenty five percent of the residents are <15 years of age. Fifteen percent of Roxbury residents >18 years of age have had less than a ninth-grade education, as compared with 8.7% in Boston overall. The Roxbury unemployment rate (14.6%) and median household income ($19,351) compare unfavorably with corresponding data for the entire city of Boston ($29,180).3

Several major medical centers within and adjacent to Roxbury are tertiary care institutions, including a National Cancer Institute-designated Comprehensive Cancer Center. The cancer focus of these hospitals is on the treatment of patients who have been diagnosed with malignant tumors. However, reduction of cancer morbidity and mortality requires the avoidance of exposures to environmental carcinogens, including tobacco products, unhealthy diets, and asbestos insulation in poorly maintained houses in the community. Additionally, screening for early detection of the breast, cervix, colon, and other cancers needs to be available and affordable to the underserved population of Roxbury. Although early detection tests are available at the neighboring tertiary health centers, the services might not be readily accessible, affordable, and acceptable to the community, particularly for people who are uninsured or underinsured. In contrast, the mission of neighborhood health centers in Roxbury is to serve those in need by providing culturally appropriate care. For example, Patient Navigators can be trained to help the elderly, seriously ill, and non-English-speaking patients to receive essential medical services, and seek payment for examinations, medications, and follow-up care (7, 8). However, these tasks are labor intensive, costly, and often not reimbursed. Because underserved minority populations tend to have higher cancer incidence and mortality rates, the “war on cancer” will not be successful until access to effective interventions are available to people with increased risk. Part of the solution lies within community coalitions and neighborhood health centers that are essential partners in efforts to reduce the cancer burden in the United States.

An Ethnic-specific Focus: COHS. The Roxbury community is composed of different ethnic groups, yet COHS focuses on the African-American population. The decision to have a narrow ethnic-specific focus has both an upside and a downside. Public health professionals usually define a population geographically, e.g., by neighborhood, thus losing the capacity to be historically, culturally, and ethnically competent and specific. Although certain universal themes cross ethnic groups, strategies and actions can be made historically and culturally appropriate with a narrower focus. Coalitions such as COHS (small, neighborhood-specific, and targeting specific health behaviors) can more easily focus on a specific ethnic group and the diversity within that group. Broader-based initiatives often choose more universal themes addressing a multiethnic group. Although the target population is African-Americans in Roxbury, the coalition is composed of ethnically diverse groups of practitioners and Roxbury residents.

The theoretical basis of COHS is the understanding and addressing of racism as a necessary strategy for reducing health disparities, and appreciating the lessons learned from contemporary successful social transformation models. COHS focuses on the African-American population of Roxbury to identify specific explanations for disparities in their health status: (a) excess disease occurrence; (b) poor health status during the era of slavery; (c) historical second-class citizenship after emancipation; (d) greater institutional barriers to services for racial minorities; (e) differential treatment by race; (f) differential access to health information by race; and (g) compromised commitment to wellness.

Differences in disease occurrences are familiar to people studying disparities in cancer outcomes (point a). However, the six other explanations often go unexplored. Historical issues are often overlooked, because they appear to have little contemporary relevance (points b and c). The next few points (points d–g) parallel the levels of racism. COHS meetings have examined specific institutional barriers and experiences, with differential treatment based on the perceptions by the medical community of African-American patients from Roxbury. Point g (compromised commitment to health) was difficult to name and accept, as COHS tried to capture the manifestations of institutionalized racism; its inclusion acknowledges the negative impact of internalized racism on feelings of self-worth, entitlement to medical services, and self-advocacy. Thus, COHS addresses the differences in health outcomes that result from three different levels of racism, i.e., institutional, interpersonal, and internalized racism. COHS strategies can help other coalitions tackle the problem of cancer disparities, because the lessons are broadly applicable. Causes of excess cancer morbidity and mortality are also risk factors for other health problems such as cardiovascular disease.

Because racism is a significant source of stress and ill health among African-Americans, a mission of COHS is to improve health among African-Americans in Roxbury by reducing cancer and heart disease risk factors (unhealthy diet, inactivity, obesity, and smoking), and confronting racism directly. A Centers for Disease Control Phase I REACH (Racial to Ethnic Approaches to Community Health) Grant funded the Harvard School of Public Health as the Central Coordinating Organization for COHS. The current partners include local community-based organizations, Brigham and Women’s Hospital, and four neighborhood health centers (Bowdoin, Dimock, RoxComp, and Martha Eliott). COHS has an administrative unit and four major programmatic clusters: (a) Health Promotion cluster to increase health awareness in the community through schools, churches, health centers, and other community-based organizations, including primary and secondary prevention of heart disease (9–12); (b) Antiracism cluster to raise awareness of racism as a source of ill health, and to reduce its impact; (c) Clinical Care and Research cluster to improve access for the Roxbury residents to quality care and clinical trials; and (d) Policy Change cluster to impact on health-related public policies at the societal, environmental, and community levels that influence health outcomes. COHS uses a combination of a population-wide approach and a targeted subgroup approach as recommended in the Race Initiative Summary...
Race, Racism, and Health Disparities. African-Americans bear an excess health burden that has roots in the history of the United States. The impact of chattel slavery, Jim Crow years, and legal segregation on the health of African-Americans is well documented. The work of Byrd and Clayton (13) provides a comprehensive examination of American policies and their impact on the health of people of African descent. Table 1 (13) illustrates the 382 years of documented presence of Africans and African-Americans in the United States: 246 years or so in slavery, another 100 years of reconstruction and Jim Crow (apartheid American-style), and subsequent passage of the Civil Rights Acts 36 years ago that gave nearly full citizenship rights to African-Americans. Byrd and Clayton (13) demonstrate that public policies toward slaves, freed men and women, and African-American citizens have had a direct impact on health outcomes. These findings support the decision of the COHS Coalition to deal directly with the issues of race, racism, and health policy.

“Race” has been defined and is often used as a biological construct, but the term is increasingly acknowledged as a social construct for categorization in a race-conscious society (14–18). Race categorization is a rough proxy for socioeconomic status and culture, and it precisely captures social classification and the impact of racism in our society (19, 20). The federal initiatives to eliminate racial and ethnic disparities in health by the year 2010 highlights the importance of acknowledging, measuring, and addressing the impact of racism on health outcomes.

We use the tri-level conceptualization of racism: (a) institutionalized; (b) interpersonal (personally mediated); and (c) internalized (as illustrated in Ref. 21). Institutional racism is the differential access by race to the goods, services, and opportunities of society. It is an inherited and often legalized disadvantage within institutional structures, customs, practices, professional protocols, and law, even when there is no identifiable perpetrator. Institutionalized racism is manifested by differential access to quality education, healthcare, adequate housing, access to power, voting rights, and representation in government and media. Interpersonal Racism or personally mediated racism refers to prejudice (differential assumptions about the abilities, motives, and intents of others by race) and discrimination (differential actions toward others by race). Racism is manifested by lack of respect (e.g., poor or no service), suspicion (shopkeeper vigilance), devaluation (stifling of aspirations), scapegoating (see Rosewood incident4 and Charles Stuart case5), and dehumanization (police brutality, medical care withheld, and hate crimes). Internalized racism refers to acceptance by members of a stigmatized race of negative messages regarding their abilities and intrinsic worth. Internalized racism among African-Americans manifests as embracing “whiteness” (stratification by skin tone), self-devaluation (racial slurs as nicknames), and helplessness and hopelessness (voter nonparticipation and risky health behaviors).

African-American children are bombarded with negative images in the media regarding their ethnicity and culture from a very early age (traditional fairy tales, folklore, action-heroes, Disney movies, or cartoons). Children are aware of racial differences as early as 3 years of age. The famous doll studies have confirmed that many black children still prefer white dolls (22, 23). Many school-age African-American children have internalized negative messages, leading to low self-esteem, lack of confidence, anger, and aggressive behavior; positive reinforcements are needed to prevent internalization and stress-associated disorders (24–29).

Several models were used to identify a “practical” theoretical framework for the strategies and action plan of the COHS. Individual and societal factors contribute to the higher rates of poor health and unhealthy risk profile among African-Americans, e.g., physical inactivity is an individual choice, and the lack of safe, convenient recreational facilities also plays a role (30). Likewise, the esocultural model described by Krieger (26) contends that discrimination is “embodied” via five distinct biobehavioral and socioenvironmental pathways: (a) economic/social deprivation; (b) exposure to hazardous substances; (c) socially inflicted trauma; (d) targeted marketing of legal and illegal drugs; and (e) inadequate health care (31). Lack of health insurance also contributes to increased morbidity and mortality from cancer and other disorders. African-Americans

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4 The Rosewood Massacre of 1923 was sparked by a white housewife who alleged that a black man had entered her home and assaulted her, resulting in a white riot that destroyed the black township of Rosewood, Florida, and claimed at least eight lives. Internet address: http://www.displaysforschools.com/RosewoodHtml.
5 On October 23, 1999, Carol Stuart, a pregnant white lawyer, was shot in the head and died in the Mission Hill neighborhood of Boston. Her husband, Charles Stuart, who was also wounded, alleged that a black man had shot him and his wife. His allegations led to a massive police manhunt throughout that community. For nearly 4 months, Charles Stuart mislead the police, media, and family members before committing suicide. Internet address: http://www.dpiinfo.com/essay/charlieHtml.
are twice as likely as Caucasians to be uninsured (25% versus 14%), and, thus, receive poorer care.6

Paucity of clinical research on minority groups contributes to inadequate knowledge of clinicians. Giuliano et al. (32) found that structural, cultural, and linguistic barriers exclude minorities from research studies and academic institutions. The experience of the Tuskegee syphilis study7 on the African-American community still impacts the mistrust of the United States health care system. Moreover, even insured African-Americans with cancer receive fewer effective clinical interventions and lesser quality health care (34, 35). Patients of diverse races with similar insurance (Medicare and Medicaid) do not receive the same level of care, with racial minorities receiving less or poorer care.

After years of working in Roxbury, we have learned that meetings are critical to the organizing process, including bonding, recruiting new partners, and developing a community action plan. Activism on the part of professionals can really help to inspire, empower, mobilize a community, and restore faith and hope. Our professional-community partnerships integrate community views with public health views. Our professionals are open to constructive ways people harness resources in their own community, by serving as facilitators and human resources.

Martin Luther King, Jr. said, “No great victories are won in a war for the transformation of a whole people without total participation. Less than this will not create a new society; it will only evoke more sophisticated token amelioration.” (36) Creating an infrastructure for social transformation and catalyzing community changes are not easy. The promise of eliminating health disparities might rest on our ability to change multiple and interrelated behaviors that contribute to adverse cancer and other disease outcomes in minority populations. Thus, we continue to inventory social transformation models that might represent the theoretical basis for our action.

Both individually and collectively, people of color have fought environmental injustices. Many of these struggles were not framed as “environmental” problems, but as “social” problems. For example, the 1968 United States National Advisory Commission on Civil Disorders discovered that the systematic neglect of garbage collection and sanitation services in African-American neighborhoods contributed to the urban disturbances in the 1960s. In some communities, unpaved streets, and lack of sewers and indoor plumbing were environmental problems in the 1960s, and continue to be environmental problems today. Nevertheless, exercising the right to know, inspect, and negotiate encourages the prevention of chemical and other hazards. Activism can revitalize a community, restoring its faith in the democratic process. Grassroots leaders often emerge from groups of concerned citizens (many of them women) who see their families, homes, and communities threatened by some type of polluting industry or governmental policy.

Cultural activism is another form of political action practiced by many grassroots groups to transform communities around social issues, and gives a voice to people. It is a strategy for social change and liberation, gaining political power, and building political unity. Cultural activism develops a community by connecting diverse people, and converts them from spectators to activists. The civil rights movement, the struggles for women’s rights, and the fight against AIDS are examples of organizing to reduce health disparities and to facilitate social change. Using the culture of a community to promote healthy lifestyles and behaviors can be a powerful tool of building community and empowerment. The creation and reaffirmation of community culture can advance grassroots organizing for reducing health disparities. Identifying shared history is a way of building community solidarity. The crisis in health disparities is a potentially uniting phenomenon that can link seemingly separate issues and peoples. How will people imagine a society that transcends racism, sexism, and class? Social transformation means rethinking these relations.

References


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