

MEETING THE CHALLENGES OF CANCER PREVENTION AND CONTROL IN SOUTH CAROLINA:

Focusing on Seven Cancer Sites, Engaging Partners

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Cancer is a set of diseases that affects everyone, though the incidence and severity of specific cancers varies considerably (sometimes several hundred-fold) from place to place and across populations. A little over a year ago, the South Carolina Medical Association set a national precedent by devoting an entire special issue of *The eJournal* to cancer prevention and control.¹ At that time, we challenged our colleagues, community activists, cancer survivors, and others to respond to those articles that comprised the July 2005 special issue. The current issue reflects the very careful response of individuals from many constituencies who have an interest in cancer prevention and control, and the thoughtful peer review of the seven cancer site-specific articles by scientists around the country and the world. This *Journal* issue consists of these seven research papers and four articles by community partners speaking from a variety of constituent perspectives.

Although we have made considerable progress in the past year, South Carolinians continue to experience some of the highest cancer incidence rates in the world.^{2,3} Relative to other populations, our mortality rates are even more striking.^{2,4} Marked disparities in cancer incidence and mortality rates in African Americans drive the overall high rates of cancer in South Carolina.² While some of the differences, especially in mortality, are related to socioeconomic factors that determine access to care, we are pretty much in the dark regarding many of the underlying causes.⁵⁻⁸

Despite that racial designations are far from perfect, the epidemiologic evidence is consistent with race (geographic origin), rather than skin color, being related more strongly to known or suspected cultural and biological determinants of cancer.⁸⁻¹² In the US as a whole, as in South Carolina, the designations “White” and “Black” are used when collecting data for purposes of cancer registration. The reality is that the vast majority of Blacks are of predominantly African origin (African American) and the vast majority of Whites are of predominantly European origin (European American). So, when we are focusing on underlying causes of disease and discussing conceptual issues around research and care we use the more

accurate, if still imperfect, terms “African American” and “European American.” When we refer specifically to registry data we use the terms employed by the registries (i.e., Black and White).

The seven scientific articles that form the basis of this special issue of *The Journal* highlight the most significant of South Carolina’s cancer disparities. In 2003, we began a process of very actively engaging the community in research related to cancer disparities. This began by bringing the *Cancer Research Needs Report of the South Carolina Cancer Research Network (CRN)*¹³ to the attention of activists in the community. This method of active engagement has continued to expand through the South Carolina Cancer Disparities Community Network (SCCDCN – <http://sccdcn.sph.sc.edu>), one of 25 centers funded through the NCI’s Community Networks Program. The seven scientific articles and the four pieces by community partners reflect the dialogue that has continued to develop across our various constituencies.

While each of the relevant constituencies might be inclined to focus on a single aspect of prevention, the Community Network defines the scope of cancer prevention and control very broadly, to include:

- Primary prevention (i.e., focusing on factors such as diet and physical activity that may modify the probability of getting cancer and therefore would have a direct effect on incidence). For some cancers, including three on which we focus here (i.e., cervical, colorectal, and oral), screening is a primary preventive and not just a method of early detection (as the detected lesion may be precancerous).
- Secondary prevention (i.e., directing attention toward issues such as early detection to downstage disease at the time of diagnosis, and factors that may modify the likelihood of survival and recurrence and therefore have an effect on prevalence)
- Tertiary prevention (i.e., examining factors that would influence quality of life, but not necessarily change either incidence or prevalence)

The SCCDCN (Community Network) defines its scope and

direction in very broad terms. Its predominant theme is community-based participatory research (CBPR) designed to encompass a broad array of community, consumer, clinical, basic science, and public health perspectives. We intend to serve the broad constituencies who diagnose and treat people with cancer, those who are in high-risk groups or already have been diagnosed with a cancer, and researchers who are charged with understanding the full range of cancer prevention and control issues. The main focus is on research, but this is defined in the broadest terms possible to include studies ranging from gene-environment interactions to health policy-related issues. Given the discordance between real and perceived risk across an array of public health issues,¹⁴⁻¹⁷ we also define education as fundamental to our purpose. Furthermore, we see education as something from which any and all of the constituencies may benefit.

Each of the seven cancer site-specific articles presents the descriptive epidemiology of the cancer, discusses issues around screening, and describes special cancer prevention and control activities and programs that exist in South Carolina. While the articles stop short of proposing advocacy and public policy positions, there are clear implications for what we know and should do something about. Likewise, areas for future research are outlined – and these range from understanding basic disease etiology to educational programs and interventions to health policy research. One of our goals is to engage the broad range of our constituencies in thinking in creative ways about tackling the cancer problem. An important constituency is the readership of *The Journal of the South Carolina Medical Association*.

As a member of the National Cancer Institute's Community Networks Program, the Community Network was designed specifically to address South Carolina's cancer problem by engaging those individuals and communities at greatest risk of getting and dying of cancer. The community-based participatory research (CBPR) approach it uses involves community members in understanding the problem and in defining the scope of the research question.^{18,19} These community members work with academic researchers and health-care providers in the design and implementation of research studies; and indeed in setting the research agenda. Their input, which reflects a desire to be partners, ensures that we pose the best questions to move us along in addressing cancer disparities. Because many of the underlying causes of specific cancers are causally related to other cancers and disorders that disproportionately affect racial, ethnic, and underserved minorities, this work holds great promise for having positive impacts on people's lives.

While many South Carolinians know that rates of most chronic diseases, including many cancers, are elevated in our state, few understand just how little our understanding may be advanced by findings obtained from research conducted in other parts of the country or the world. Good scientific research is designed to produce results that can be generalized beyond the populations in which the studies were conducted (hence, the rationale for doing research in animals). However, it is clear from reading the articles in this issue that findings from these studies often fall short of the goal of being applicable everywhere. Research conducted elsewhere – or spearheaded by scientists based elsewhere – runs the risk of not leading to practical advancement of knowledge as to why rates of these cancers are so much higher in South Carolina.

Although there are some surprises in terms of what is happening in South Carolina, these articles will reinforce what well-informed researchers and practitioners know. The cancers of the upper aerodigestive tract (oral, esophagus, and lung) are strongly associated with tobacco use. From professional, personal, and political perspectives we know that we should limit and discourage tobacco use. However, what seems to be true for European or European American populations may not hold as well for African Americans, especially in our state. For example, in South Carolina the incidence rate of squamous cell carcinoma of the esophagus, a particularly deadly cancer, is six times higher in African Americans than in European Americans.²⁰ Based on studies conducted elsewhere, predominantly in European or European American populations, the conventional thinking is that more than 95 percent of variability in this particular cancer is attributable to the combination of smoking and drinking.^{21,22} It is indeed curious and troublesome that African Americans and European Americans drink at about the same rate and that African Americans actually have lower smoking rates,²³⁻²⁶ especially in South Carolina.²⁷ Clearly, there is something unusual about the underlying causes of this cancer in this population. It is equally clear that research conducted elsewhere has missed the mark in terms of explaining risk and in providing complete information about what people can do to protect themselves.

For strongly hormone-sensitive cancers (prostate and breast) striking disparities also exist. Prostate cancer rates continue to be extraordinarily high among African American men in comparison to their European American counterparts. While there is about a 55 percent elevation in prostate cancer incidence in African Americans nationally, in South Carolina the difference is close to 80 percent - about a 50 percent increase in the racial disparity seen nationally.^{2,28} Mortality rates are about 2.5 times higher in African Americans.²⁸ There is no good explanation

for why this large disparity exists, and the hardship this creates is staggering. The incidence of breast cancer, the major hormone-sensitive cancer affecting women, is about 15% lower in African Americans.²⁹ However, for a given stage of breast cancer, African American women have much more aggressive (higher grade and lower probability of hormone receptivity) disease than do European American women. Therefore, even with reasonable access to screening (and, thanks to some excellent programs, screening rates are not very much different by race in this state), African American women would be expected to do worse. Indeed, the upshot is that the breast cancer mortality rate in African American women is about 60 percent higher than what we would expect based on incidence alone.

The race-by-gender anomalies in rates also are striking – and something we would know little about without access to the superb data of the South Carolina Central Cancer Registry (SCCCR). The articles on colorectal, oral, lung, and esophageal cancers illustrate that for most cancers that afflict both genders women have lower incidence rates of disease. However, African American women have a proportionately higher incidence of cancer relative to European American women; whereas African American men tend to have rates that are more similar to their European American counterparts.

Much of what we already know in order to prevent and control human cancers has emerged from health care environments. Competent research in this arena can occur only in well-organized clinical settings that understand, appreciate, and support research. Through a process of productive engagement, clinicians and consumers help to ensure that important questions are asked; with the consequence that the findings from relevant research improve care. The levels of prevention outlined by the NCI,³⁰⁻³⁴ beginning with basic science (encompassing both “wet lab” and epidemiologic research) and culminating with health policy research, can and should be integrated with clinical and public health practice. In fact, the full range of such activities can be incorporated into single programs, and often single studies. By working together we greatly limit the likelihood of working in the “silo” mentality that characterizes much of the War on Cancer.³⁵ In this way we can work so that we:

- avoid “exquisitely irrelevant” results on the basic science side of things,
- obtain important etiologic clues that can be gleaned in clinical practice,
- place our work in the proper personal and public health contexts, and
- address the complex array of community factors that determine the occurrence and outcomes of cancer.

Ultimately, failures in any of these cause us to waste precious human resources.

Cancer research in South Carolina should not be limited to etiologic studies. However, given the provocative findings of the descriptive epidemiologies of these cancers presented in this issue, conducting well-designed analytic epidemiologic studies must be one of our priorities. Other kinds of studies, including dissemination of smoking cessation, cancer screening, and community-based dietary and physical activity programs need to be undertaken. Also, competent evaluation and health services research can (and should) be conducted as part of outreach and access to care. Our goal, of course, is to address the full range of prevention (from primary prevention to palliation of symptoms and reduction of suffering) and to go beyond outreach. The South Carolina Cancer Disparities Community Network’s intention is to engage. We begin from an understanding that no one person or group has all the answers. It is our collective intelligence and wisdom that will meet the challenge of these cancer disparities. We must create a dialogue that addresses cancer from all of its many facets. We are grateful to have the will and perspectives of the community expressed in this special issue of *The Journal* – another precedent for which the South Carolina Medical Association can be justifiably proud.

While the primary interest of many readers of *The Journal* is focused on the health of individuals, the remarkable improvements in longevity and quality of life that humans have experienced in the past century and a half have come from a collective commitment to improve population health.^{36,37} Although physicians and other health care providers are probably the single most important constituency in changing individuals’ health-related behaviors and attitudes about those behaviors,³⁸⁻⁴¹ there is only so much any individual can do to create durable change in communities and the larger populations they comprise. Long-term change in the health status of populations must combine personal and institutional accountability.⁴²

As health professionals, we need to remind ourselves of how the people we serve lead their lives. People live in families and larger communities – workplaces, schools, community organizations, and places of worship, among others. The willingness to seek medical care or enroll in a research study is conditioned by interactions with you, physicians and other health care providers, and the barriers that exist in communities at all levels. About half of all cancer patients want the opportunity to participate in research studies, especially intervention trials that may either increase survival or improve quality of life, or both.⁴³⁻⁴⁹ Even more people (including both cancer patients and disease-

free subjects) are willing to participate in observational studies. These studies can help answer the kinds of questions that address our high cancer rates. Despite this, few adult cancer patients actually participate.⁵⁰⁻⁵² Even fewer African American cancer patients choose to participate.⁵³ Therefore, we all must be engaged in cancer prevention and control efforts, including designing studies that are seen by potential participants as desirable and relevant to their lives. South Carolina stands ready to make a significant contribution to cancer research locally, as well as regionally, nationally, and internationally. We all need to work together to make sure that those who are at highest risk of getting cancer and who will suffer the most once they get the disease are being served. We need to encourage dialogue and involvement. We are making progress, but we have a long way to go.

Context and collaboration are crucial to addressing the many dimensions and facets of cancer prevention and control and the research needed to drive progress. Founded in 2003, the South Carolina Cancer Alliance (SCCA) is an organization of nearly 900 members, including more than 140 institutional members, and many individual members who are also SCMA members. The SCCA (www.sccanceralliance.org) has been instrumental in acting as an umbrella for many of the cancer prevention and control activities in the state. Unlike any other organization in the US, the SCCA creates a real, statewide focus for cancer prevention and control activities. It is with a sense of appreciation and gratitude that we acknowledge the work of the SCCA and its many affiliates. In particular, we would like to point out work by the South Carolina Department of Health and Environmental Control (DHEC) and its South Carolina Central Cancer Registry (SCCCR). The SCCCR has consistently received the highest ratings from the North American Association of Central Cancer Registries and the National Program of Cancer Registries. Without the dedication of the SCCCR staff and their commitment to excellence, this special issue of *The Journal* would not have been possible. Besides their work in supporting rigorous use of the registry data by academicians, the SCCCR has a wonderful interface accessible to both health professionals and the lay public who wish to query cancer-related facts.

In 2005, we pointed to the South Carolina Cancer Report Card as an example of the kind of excellent collaboration that exists in few, if any, places in the US.⁵⁴ In developing the 2005 Report Card (see www.sccanceralliance.org), which focused largely on cancer rate differences, the SCCA epidemiologist (Dr. Virginie Daguise) acted as the SCCA liaison to the registry for data requests. This year's Report Card, which focuses on mortality-to-incidence ratios to identify areas of particularly

virulent disease and examines policies that have a direct impact on cancer rates, represents an attempt to move beyond mere description of the "cancer problem."

The SCCA is the major partner with DHEC in the development of the new Comprehensive Cancer Control Plan for South Carolina (CCCPC – also see www.sccanceralliance.org). Our intention for the current plan is to create a living document that can change easily as our knowledge base increases and as we improve in primary prevention, screening, and treatment of cancer. It also is intended that this plan emphasize implementation and be very accessible to researchers, health-care providers, and the general population.

Public awareness lays the foundation for accountability in effecting health policy change and, as noted, progress is being made on various fronts in community engagement in South Carolina. However, moving to health policy formulation at a state level is problematic. While state health policies often do have a significant impact on the health of its residents, state policymaking is not highly interactive.⁵⁵ Public input and awareness tends to be lower at the state level than the federal level and policymaking at the state level is more strongly influenced by special interest groups. African Americans are less likely to participate in the political process than European Americans at both the federal and state levels. Also, the majority of European Americans (67%) are not aware of racial and ethnic health disparities.⁵⁶

So, to the extent that the clinicians and researchers are willing to create awareness and advocate for those in greatest need of services, we can help to fill the obvious gap. Examples of effective bridging include: 1) the agreement of The Black Caucus of South Carolina Legislators to partner with the SCCDCN (Community Network) to look at ways to reduce cancer health disparities; and 2) South Carolina's adoption of expanded Medicaid coverage for the treatment of breast cancer; and 3) setting aside \$1 million dollars in the state budget for the treatment of breast and cervical cancer. Challenges for the future include moving South Carolina out of the group of 31 states that do not require health insurance companies to pay for colorectal cancer screening (one of three cancers for which we can screen for primary prevention) and having South Carolina become one of the majority of states that have legislation or special agreements requiring health plans to pay for medical care received by clinical trial participants. To our knowledge, a complete analysis of all such policies and programs has never been completed. Just as medical practice is best conducted when based on strong scientific evidence, we believe an assessment of this kind will equip the public and policy-makers with evidence-based in-

formation to inform policy and program directions aimed at reducing cancer disparities in South Carolina. The findings are of some importance because over half of African Americans are poor or near poor, 20% have no health insurance, and inefficiently delivered health care is very expensive.⁵⁷

This special issue of *The Journal of the South Carolina Medical Association* represents a major step forward in our commitment to work collectively on a major issue of clinical and public health importance. Along with the South Carolina Cancer Alliance and its affiliates and members (especially SC DHEC) this places us in the vanguard of cancer research and treatment in the United States.

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