

Cancer Disparities: Unmet Challenges in the Elimination of Disparities

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We are the hollow men, we are the stuffed men, leaning together, headpiece filled with straw. Alas!

--*TS Eliot, 1925*

The first twenty years of publication of *Cancer Epidemiology, Biomarkers, & Prevention* occurred during a period of increased attention to health disparities and advances in knowledge about their determinants. Yet while some questions have been answered, new, arguably more sophisticated and complex questions have come to light. Consequently, many challenges to our ability to ameliorate cancer and other disparities remain. After briefly characterizing the current state of knowledge about health disparities in the United States, we comment on the major challenges facing health disparities researchers and practitioners today.

Although the collection of detailed information on race and ethnicity was a goal of SEER since its inception in 1973, it was not until the 1990 census that mortality data by ethnic group for cancer and other major diseases was available for all 50 states. This more detailed information drew public attention to racial and ethnic health disparities, ultimately leading to a number of federal initiatives aimed at addressing those disparities. President Clinton's 1998 Racial and Ethnic Health Disparities Initiative (1) set an ambitious goal of eliminating racial and ethnic disparities by 2010, and \$400 million from Clinton's balanced budget plan was devoted to disparities research. The U.S. Department of Health and Human Services took leadership of the effort and set eliminating health disparities as one of the two overarching goals of Healthy People 2010 (2). In 2000, the National Center for Minority Health and Health Disparities was established under the Minority Health and Health Disparities Research and Education Act (3).

In 2003, the National Cancer Institute (NCI), in concert with the National Institute for Environmental Health Sciences, and the National Institute of Aging devoted \$60.5 million to the Centers for Population Health and Health Disparities Initiative, which is now in its second cycle of funding. Five of the eight centers during the first funding cycle focused on cancer disparities. In the second cycle, NCI has partnered with the National Heart Lung and Blood Institute, and five of the ten funded centers focus on cancer disparities.

Despite increased attention to health disparities and advances in our understanding of their determinants, we have made little headway in reducing disparities at the population level. Disparities in cancer, cardiovascular disease, obesity, diabetes, and other chronic diseases have been documented extensively in the public health record. These disparities can be summed as the gap in life expectancy between urban black males and Asian males (15.4 y) (4). Yet, despite clear documentation and elegant quantification of disparities, our population health response has been limited in its effectiveness to eliminate disparities. Does this academic and public health services response reflect on us collectively as a headpiece filled with straw?

### **Multilevel Models of Cancer Disparities**

Investigators from the Centers for Population Health and Health Disparities (CPHHD), representing a range of populations and cancers, collaborated to define a model that would help frame research and speed understanding across disciplines and between providers, communities, and public health agents (5). The conceptual framework for cancer disparities was developed by Warnecke et al. (including Dr. Gehlert) to address the question, "How does population risk relate to individual risk?" (5), drawing from their own work as part of the CPHHD and from the work of

other leaders in the field (6, 7, 8) to address this question from a multilevel perspective. The major implication of the model is that multiple levels of influence from the microbiological to the societal interact in complex ways to produce cancer disparities. The framework for analysis of population health and health disparities includes three primary levels of determinants, namely distal, intermediate and proximal.

Distal determinants include population-level social conditions such as variation in rates of disease or poverty. Their roots are embedded in shared social norms about health or social practices, and socioeconomic disadvantage.

Intermediate determinants include the immediate social and physical contexts and social relationships in which the distal effects are experienced, such as the community or neighborhood. The social context includes the extent of residential segregation and opportunities for social interaction to redress the effect of the distal factors. Also included is the accessibility of local health care resources to the public, availability of transportation and quality of the built environment. The intermediate determinants are the links through which the environment affects individual demographic factors as well as biologic responses that compose the proximal determinants. Demographic factors refer to both contexts and individuals and in the model can have independent effects.

Proximal determinants include biological and genetic factors such as ancestry and family history of disease. They also include individual-level factors such as demographics and health behavior.

### **Implications for Cancer Disparities Research**

Research has evolved from merely describing disparities to refining approaches that allow us to mount appropriate public health responses. The multiple levels of

investigation suggested by the CPHHD model map across a range of scientific disciplines, from the biological/genetic to the social, each potentially bringing its own siloed approach and blinkered way of conducting and reporting research. This occurs in part because of our limited capacity to promote and sustain communication across disciplinary boundaries, thus impeding our progress in understanding and acting to eliminate disparities. Extensive study of the genome over the past decade, for example, has advanced our understanding of the carcinogenic process, yet limited understanding of the interplay between genome and environment in relation to disease risk or outcomes has slowed our translation to treatment and prevention. Understanding the genome and its role in behaviors has a great deal of potential. We note, for example, some progress on nicotine addiction, in which genetic predisposition may vary by SNPs that track with genetic origins of populations (9, 10) and have important implications for addiction, and cessation from use of tobacco products, hence instantly important for the inordinate health burden caused by tobacco.

A clear definition of models to advance our insights into the causes of cancer disparities and frame comprehensive programs and solutions to them depends on our ability to work transdisciplinarily, in a way that transcends disciplinary boundaries. Although transdisciplinary approaches to science are in their infancy, they potentially can help us to capture the complexity of phenomena like cancer disparities, by virtue of providing a blueprint for how to talk across disciplines and to translate lessons from animal models to humans to whole populations. The ability to communicate across disciplines will allow us to more fully capture the complex ways in which the determinants at the distal, intermediate, and proximal levels interact with one another to fuel cancer disparities.

In addition to their role in the design of cancer disparities research, it is also important to consider the implication of multilevel models for the design and action for elimination of disparities. Research studies always should be designed with an eye toward informing subsequent implementation, as well as ensuring sustainable change after an intervention is completed. As an example, translating the discoveries of variation in nicotine addiction mentioned above (9) into public health interventions requires translation and implementation at a number of junctures. First, affordable clinical tests to determine propensity for addiction must be developed, tested, and introduced into clinical practice. Then, smoking cessation interventions tailored to nicotine-addiction subgroups must be developed, tested, and introduced into provider systems in a way that heightens the likelihood of their acceptance and use. Lastly, some means of sustaining their use through time is needed, perhaps through disseminating information about their utility and effectiveness to providers and the general public. It is reasonable to assume that the extent to which “implementers” along the chain are familiar with the work of others who preceded them will in part determine the success of their own efforts. Familiarity with discoveries of variation in nicotine addiction, for example, will allow primary care providers to better explain the virtues of smoking cessation interventions to their patients. Likewise, social marketers have to know the results of effectiveness trials, and so on.

### **Current Challenges to Cancer Disparities Research**

A number of challenges remain to our ability to understand the determinants of health disparities and successfully translate that understanding into successful interventions to decrease cancer disparities at the population level. The three major challenges are how to consider race and ethnicity in disparities research (i.e., what

is the place of race and ethnicity in health disparities research), how best to translate discoveries into public health solutions to cancer disparities, and how to create a research environment that allows for the successful execution of multilevel research.

**Race and Ethnicity in Cancer Disparities Research.** Since the time of Clinton's 1998 Racial and Ethnic Health Disparities Act, there has been a tendency to conflate health disparities research with minority health research. More often than not, group comparisons are done by race/ethnicity, often without a strong conceptual basis for doing so. We argue that this has resulted in an emphasis on race and ethnicity as determinants of cancer disparities over socioeconomic status or other factors. This has occurred despite ample and growing evidence of the effect of social determinants on disparities and problems with defining and measuring race (11). Gehlert and colleagues, for example, found that social measures such as exposure to crime and social isolation were significantly associated with lack of estrogen and progesterone receptor expression among African-American women newly diagnosed with breast cancer in Chicago (12).

Meara and colleagues discovered that the picture for gains in life expectancy through time by race and gender changes markedly when groups are again divided into low and high levels of education (13). The authors found, for example, that life expectancy at age 25 years declined for both African-American and white women with low levels of education while it increased for women with high levels of education. In other words, the addition of a social factor changed the way that race operated in life expectancy gains.

Many authors have questioned the utility of race in research (14). Without repeating those arguments, we note that self-reported race/ethnicity, the norm in

health disparities research, does not always match genotype (15, 16). Thus, racial and ethnic groups based on self-report may not accurately allow the comparisons that investigators intend to make, if self-reported race was intended to be a proxy for genotype. This could affect the results of their work and the conclusions drawn from those results, rendering the interventions, practices, and policies derived less suitable and effective.

The elimination of cancer disparities relies on a much more nuanced understanding of what underlies those disparities, as well as the complex ways in which factors at multiple levels of influence interact with one another, than tacitly basing research design on cross-race comparisons. Race/ethnicity is now more likely to be measured in public health statistics than education or other social variables. Comparing first by race/ethnicity presumes significant biological differences that may not be pertinent to the cancer disparities issue under investigation, and may draw attention away from other, more significant, determinants. Likewise, comparisons across racial and ethnic groups that rely solely on self-report of race/ethnicity may produce error.

**Translating Discoveries into Effective Interventions.** From the outset of training to early narrowing of research focus and the successful launching of academic careers, our research system is focused on fostering excellence, scientific discoveries, and career advancement, usually tied to publication and funding records. This system then rewards isolated researchers who make noteworthy “discoveries”. Application or translation of discovery to impact or implementation is of far lower stature.

While favoring discovery over translation and application of findings doubtless has launched a high number of successful careers, it has had less of an

impact on the nation's health disparities. Arguably impacting disparities that are known to have multilevel determinants not only requires an appreciation of the work of translational science and scientists, but also requires that scientists at each stage of the continuum from discovery to translation have the opportunity and skills to communicate with one another. In addition, it is important to recognize that, for maximum effectiveness, this communication must be bidirectional. Research ideas must move not just from bench to population but also from population back to bench.

Moving from discovery to application brings society the full return on our collective investment in research. For example, in 2008, biomedical research expenditures in the United States exceeded \$100 billion on health-related research (17, 18). Only a small fraction of the 30 billion NIH component was expended on prevention research (19, 20)—i.e., the direct and immediate application of effective intervention strategies to benefit the public's health (p.93)(21). Despite this low priority, the NIH maintains an active program in "dissemination" research, albeit with an extremely low level of funding. Across all funding sources through 2008 — federal and foundations—spending on health services research, models of care, and service innovations, represented only about 1.5% of biomedical research funding (22). With few resources little attention is paid to the translation of scientific discovery to effective programs.

**Executing Successful Multilevel Research.** Executing successful multilevel research depends on the ability to visualize the multiple influences on cancer and cancer disparities and understand the complex ways in which they interact with one another to produce worse outcomes for some groups than others. This can neither be done by a single investigator nor a single discipline. Yet, despite

a growing emphasis on transdisciplinary research, few research teams have achieved transdisciplinary functioning.

Operating transdisciplinarily is not intuitive and requires training and education and support. For the most part disciplinary scholars continue to be trained primarily in the language and methods of their own individual fields of training. Although scattered transdisciplinary training programs exist, they have not been systematically integrated into formal educational curricula. This lack of systematic training in transdisciplinary science reinforces the siloed nature of research and hinders the transfer of knowledge across disciplines.

This lack of attention to the transdisciplinary training of students is mirrored in the governance of faculty by institutional administrators. In general, the science of transdisciplinary research has been inadequately recognized within academia for its contribution to clinical and public health outcomes. Appointment and promotion committees traditionally focus on new advances in understanding and research that “changes the field”, ascribing a lower status to the application of scientific advances to improve health care delivery and well-being of the community. Appointment and promotion guidelines that emphasize the contribution of transdisciplinary research and the time required for integrating research with practice will help set the standard for this aspect of research and practice to be valued and rewarded. Alternatively, a metric that captures the public health impact associated with each activity (research, teaching, and service) may have added benefits of creating demand for investment of time and funding in higher-yielding research and allowing comparison of the relative value of transdisciplinary research.

Just as structural changes are needed to stimulate lasting behavior change by individuals, we might also consider such structural changes as priorities within

the academy, to provide incentives for increasing implementation of evidence-based practices to reduce health disparities. Like other areas of modern public health research, integrating transdisciplinary research into practice also requires substantial team work and time, in part through building and sustaining community relationships. These are aspects of population health sciences that may be harder to quantify in a way that can be consistently measured as contributions by individual faculty members. Metrics that can be reported for promotions will again be a necessary step to valuing this aspect of public health practice.

To engage community participants in research, which truly is necessary for translating discovery into public health practice, it is essential for academic centers to have a sustained presence in communities. These may be geographic communities, but also may include virtual communities, in the case of rare or uncommon conditions. They also may involve working with community organizations rather than directly with individuals experiencing health problems. This occurs in the case of individuals who do not identify as being part of a group, such as mothers of severely overweight children, substance abusers, or women experiencing intimate partner violence. Few sustained community and academic partnerships have succeeded, reflecting in part the expectation as noted by Richmond in 1968 (23) that with NIH funding clinical research centers, they would focus inwards and ignore the source population from which the participants, leading to medical research disconnected from the community and broader society.

From the community perspective, a major challenge includes the accountability structure for public health and clinical research matching community-defined priorities for the elimination of disparities, if those priorities can be articulated. Furthermore, the coordination of community assessment and delivery

of activities is often fragmented due to exigencies of funding streams, yet at the community level an integrated implementation makes most sense. Achieving integration may require a more coordinated set of activities from academic partners collaborating in linking research with implementation. In the worst (but perhaps most typical) scenario, researchers do not coordinate their efforts to engage community partners, leaving communities overwhelmed with requests and conflicting requests. Cancer centers and academic-community networks can play an important role in coordinating these relationships and ensuring that engagement with communities is appropriate and effective.

Community-based participatory research (CBPR) methods offer a means of improving engagement with communities and enhancing the relevance and effectiveness of public health interventions (24, 25, 26). CBPR relies on a collaborative partnership that equitably and actively involves community partners in all aspects of the research process (27, 28, 29, 30). Effective CBPR partnerships build expertise and capacity in the community for research and prevention, and thus have significant potential to make a sustainable impact.

Accountability is challenging when we set forth long-term goals for community needs. Are our public health schools, our medical schools, or our local health departments and administrative structures held accountable for meeting the community needs? If yes, by whom? If no, where does this responsibility rest?

## **Discussion**

The very fact that much has been accomplished over the past 20 years to increase our understanding of cancer disparities makes moving forward to ameliorate those disparities even more of an imperative. Reorientation of research trajectories, rewards, and institutional policies and commitment will be necessary to adequately

address the challenges to ameliorating those disparities. We hope that documenting the need for multi-level approaches to research and implementation and providing some idea of what it will take to implement those approaches will help to turn the straw-headedness of the past into efficient brain functioning in the future. Our efforts are aimed at funding bodies and research groups to reorient their plans and strategies to frame research and implementation from conceptualization to data collection, analysis and action, so that it is readily translated to full scale implementation that addresses simultaneously the many levels of change that will be necessary to eliminate disparities. Likewise, we challenge institutions of learning to adapt their curricular structures to provide transdisciplinary research education as early in the educational process as possible. We emphasize the value of working in partnership with communities, defined in more nuanced ways than has always been the case in the past. In this way, we can traverse the path from discovery to public health approaches to eliminating cancer disparities.

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