

**MEETING SUMMARY
PRESIDENT'S CANCER PANEL
AMERICA'S DEMOGRAPHIC AND CULTURAL TRANSFORMATION:
IMPLICATIONS FOR THE CANCER ENTERPRISE**

December 9, 2009
Wilmington, Delaware

OVERVIEW

This meeting was the third in the President's Cancer Panel's (PCP, the Panel) 2009-2010 series, *America's Demographic and Cultural Transformation: Implications for the Cancer Enterprise*. The agenda for the meeting was organized into two discussion panels.

PARTICIPANTS

President's Cancer Panel

LaSalle D. Leffall, Jr., M.D., F.A.C.S., Chair
Margaret Kripke, Ph.D.

National Cancer Institute (NCI), National Institutes of Health (NIH)

Abby Sandler, Ph.D., Executive Secretary, PCP
Gwen Darien, NCI Director's Consumer Liaison Group

Speakers

Otis Brawley, M.D., Chief Medical Officer, American Cancer Society (ACS)
Moon S. Chen, Jr., Ph.D., M.P.H., Associate Director for Population Research and Cancer Disparities, University of California Davis Cancer Center
Jean G. Ford, M.D., Associate Professor, Epidemiology, Johns Hopkins Bloomberg School of Public Health
Francesca Gany, M.D., M.S., Director, Center for Immigrant Health, New York University (NYU) Medical Center
Yolanda Partida, M.S.W., M.P.A., D.P.A., National Program Director, Hablamos Juntos
Daniel Petereit, M.D., Oncologist, John T. Vucurevich Cancer Care Institute
Timothy Rebbeck, Ph.D., Director, Center for Population Health and Health Disparities, University of Pennsylvania
Michelle van Ryn, Ph.D., Associate Professor, Department of Family Medicine, Masonic Cancer Center, University of Minnesota

OPENING REMARKS—LaSALLE D. LEFFALL, JR., M.D., F.A.C.S.

On behalf of the Panel, Dr. Leffall welcomed invited participants and the public to the meeting. He introduced Panel members, provided a brief overview of the history and purpose of the Panel, and described the aims of the current series of meetings.

Dr. Kripke reported that the President's Cancer Panel Environmental Factors Development Working Group met on October 22, 2009, to discuss the content and form of the upcoming report on environmental

factors in cancer, which is based on the Panel's 2008-2009 series of meetings. The Working Group recommended that the report be finalized and that the draft report be sent to layout. Dr. Kripke's motion to accept the Working Group's recommendations was unanimously passed.

Dr. Kripke also reported that the President's Cancer Panel Working Group on America's Cultural Transformation and Cancer met on October 27, 2009, to discuss the format of the 2009-2010 meeting series and other logistical considerations. The Working Group recommended that future open meetings in the 2009-2010 series conform to the logistics of previous meetings. Additionally, in light of testimony presented during the series concerning the non-renewal of the Cancer Information Service (CIS) contract, the Working Group recommended that NCI provide an update on communication and outreach activities planned for 2010 and beyond. Dr. Kripke's motion to accept the Working Group's recommendations was unanimously passed.

PANEL I

DR. MOON CHEN:

ASIAN AMERICANS AND PACIFIC ISLANDERS IN THE U.S. DEMOGRAPHIC AND CULTURAL TRANSFORMATION: IMPLICATIONS FOR THE CANCER ENTERPRISE

Background

Moon S. Chen, Jr., is Professor, Division of Hematology and Oncology, Department of Internal Medicine, University of California, Davis School of Medicine, and Associate Director for Population Research and Cancer Disparities at the University of California, Davis Cancer Center in Sacramento. He has been the Principal Investigator for the NCI-funded Asian American Network for Cancer Awareness Research and Training (AANCART) since April 2000. In 2008, the Director of the NIH National Center on Minority Health and Health Disparities gave AANCART the first-ever Leadership Award for its achievements in reducing health disparities. In addition, AANCART was recognized in 2009 for having the highest number of published articles among the NCI-funded Community Networks.

Key Points

- According to *World Cancer Report 2008*, cancer will be the world's leading cause of death by 2010.
- Increases in U.S. cancer incidence rates are projected to disproportionately occur among minority populations. The largest increases in cancer incidence rates are projected to be among Hispanics (142%) and Asian Americans and Pacific Islanders (APIs; 132%). The third largest increase is predicted to be among multiracial populations (i.e., those who self-identify as more than one race).
- APIs have been one of the fastest growing populations in the U.S. for several decades; however, APIs differ considerably with respect to their lands of origin (more than 30), making it impossible to address their cancer-related needs using a single approach. APIs speak over 200 languages or dialects and are extremely heterogeneous in terms of cultural traditions and socioeconomic factors (e.g., APIs constitute a large percentage of the college-educated U.S. population, but also comprise a large proportion of adults with only an elementary-level education).
- The cancer burden affecting APIs is unique—APIs are the only U.S. racial/ethnic group to experience cancer as the leading cause of death for both males and females. Cancer has been the leading cause of death for APIs since 2000. With the exception of female American Indian/Alaska Natives, all other U.S. racial/ethnic populations experience heart disease as the leading cause of death.
- In contrast to non-Hispanic whites, APIs disproportionately experience cancers of infectious origin, such as cervical, nasopharyngeal, and liver cancers. According to NCI Surveillance, Epidemiology, and End Results (SEER) data, Vietnamese women experience five times more new cases of cervical cancer than non-Hispanic white women.

- Much of the cancer burden affecting APIs could be avoided. API women are among the least likely to undergo breast cancer screening, which has been proven to save lives. Additionally, tobacco use drastically increases the cancer burden among APIs and all other Americans. More effective and culturally competent interventions to reduce cancer health disparities need to be pursued.
- APIs tend to have better dietary habits than the average American but are less likely to exercise. A National Center for Chronic Disease Prevention and Health Promotion study of Californian adults found that Asian Americans were least likely perform at least 30 minutes of moderate physical activity five or more days per week or perform vigorous physical activity for at least 20 minutes three or more days per week. Lack of physical activity is a major risk factor for cancer.
- Liver cancer represents the most important cancer disparity affecting APIs; it is also an organ site where all ethnic groups experience cancer at higher rates than non-Hispanic whites. The higher rates of hepatitis B infection in Asia, Africa, and other areas outside the U.S. may partially explain this disparity, as hepatitis B infection is associated with increased risk of liver cancer.
- Paradoxically, English fluency can either facilitate or impede the development and detection of cancer in foreign-born Americans. For example, women with limited fluency in English are less likely to be screened for cervical cancer. On the other hand, studies indicate that women more fluent in English are more likely to smoke.
- Cancer care delivery must be improved among populations with limited English proficiency and diverse cultural perspectives. Differing cultural perspectives in the clinical setting can be illustrated by how Asians show respect for their healthcare providers. Western healthcare providers expect patients to make eye contact to indicate understanding, whereas Asians consider it a sign of respect to avoid looking into a healthcare provider's eyes.
- According to U.S. Census projections, by 2050 there will be no majority population in the United States. The cultural transformation and demographic shifts in the U.S. underscore the need for providing and improving linguistically appropriate and culturally competent cancer care.

DR. OTIS BRAWLEY:

CANCER AND DISPARITIES IN HEALTH: PERSPECTIVES ON HEALTH STATISTICS AND RESEARCH QUESTIONS

Background

Dr. Otis Webb Brawley is Chief Medical and Scientific Officer and Executive Vice President of the American Cancer Society. His responsibilities at ACS include promoting the goals of cancer prevention, early detection, and quality treatment through cancer research and education. Dr. Brawley is also a key leader in the Society's work to eliminate disparities in access to quality cancer care. Dr. Brawley currently also serves as Professor of Hematology, Oncology, Medicine, and Epidemiology at Emory University. He is a medical consultant to the Cable News Network (CNN) and a member of the Centers for Disease Control and Prevention Breast and Cervical Cancer Early Detection and Control Advisory Committee. From April of 2001 to November of 2007, Dr. Brawley was Medical Director of the Georgia Cancer Center for Excellence at Grady Memorial Hospital in Atlanta, and Deputy Director for Cancer Control at the Winship Cancer Institute at Emory University. He has also previously served as a member of the ACS Prostate Cancer Committee, co-chaired the U.S. Surgeon General's Task Force on Cancer Health Disparities, served as a member of the Food and Drug Administration Oncologic Drug Advisory Committee, chaired the NIH Consensus Panel on the Treatment of Sickle Cell Disease, and filled a variety of positions at the National Cancer Institute, most recently serving as Assistant Director. He is listed by Castle Connelly as one of America's Top Doctors for Cancer. Among numerous other awards, he was a Georgia Cancer Coalition Scholar and received the Key to St. Bernard Parish for his work in the U.S. Public Health Service in the aftermath of Hurricane Katrina. Dr. Brawley is a graduate of the

University of Chicago Pritzker School of Medicine. He completed a residency in internal medicine at University Hospitals of Cleveland, Case Western Reserve University, and a fellowship in medical oncology at the National Cancer Institute.

Key Points

- The term *health disparities* refers to the fact that some populations exhibit worse outcomes than others. Disparities can be observed in disease incidence, mortality, and/or survival, as well as quality of life. Populations can be defined in a number of ways, including by race, culture, area of geographic origin, or socioeconomic status.
- The race categories used by the U.S. Census Bureau are established by the White House Office of Management and Budget approximately two years before every census. These continually evolving categories are based on politics, not biology.
- Cancer mortality rates have declined for all racial/ethnic groups combined over the past 30 years. Between 1990 and 2005, the risk of death from cancer decreased 20 percent for American men and 12-13 percent for American women. These improvements translate into approximately 550,000 American lives saved. Cancer mortality rates are declining more quickly for African Americans than for whites, but African Americans continue to have higher overall cancer death rates.
- Disparities in health need to be approached rationally. It is important to focus on things that can be changed rather than things that cannot be changed. In addition, distinctions must be drawn between social and scientific issues.
- Equal treatment yields equal outcomes among equal patients. However, not all populations receive equal treatment, a fact that must be addressed. Focusing on genetic differences between races can cause people to ignore the fact that some populations receive inadequate treatment.
- The NIH Revitalization Act of 1993 states that minorities must be included in federally sponsored clinical trials and that Phase III trials must include valid subset analyses of differences among the races. This requirement implies that disparities are due to genetic differences among the races. In addition, the required subset analyses often require oversampling of minority populations, thus placing a disproportionate amount of the risk associated with clinical trials on minorities, violating the principle of equipoise.
- Subset analyses can be misleading. Tamoxifen was approved for treatment of metastatic breast cancer based on the results of a randomized Phase III trial in metastatic breast cancer patients that demonstrated a response in approximately 30 percent of women. This study was done before assays for detection of estrogen receptor (ER) were widely available. This study was completed prior to establishment of the 1993 NIH requirements, and a subset analysis based on race was not conducted. If one had been performed, it would have shown that tamoxifen is effective in 30 percent of white women but only 10-12 percent of African-American women; this observation could have potentially led to approval of the drug for use in white but not African-American women. Subsequent research has shown that tamoxifen is effective in women whose tumors express ER, regardless of their race. This illustrates that it is important to focus more on biological markers than on race.
- It is important to think about ways to provide high-quality care, including preventive care, to all populations because disparities are influenced by factors such as utilization of screening and health insurance status.
- The notion that disparities in colorectal and breast cancer mortality between blacks and whites are due to biology has received much attention; however, these disparities did not emerge until the 1970s and 1980s, indicating that the differences are not due to genetic differences between the two populations. The emergence of disparities in colorectal cancer mortality correlates with the development of colorectal cancer screening, which is more widely utilized among whites than among blacks. Health insurance also plays a role in disparate health outcomes. For example, stage 2 colorectal cancer

patients with health insurance have a better five-year survival rate than uninsured stage 1 colorectal cancer patients, and stage 2 insured and stage 1 uninsured breast cancer patients exhibit similar five-year survival rates. It is important to note, however, that disparities among races may be due to the biological influences of environmental factors such as fast-food diets and obesity.

- Black women with breast cancer are diagnosed at younger ages than white women and tend to present with more advanced disease, higher-grade disease within stage, and fewer ER-positive tumors. In the United States, much attention is focused on identifying race-associated factors that underlie this observation. However, a Scottish study has found that poor white women in that country tend to present with more advanced disease, higher-grade disease within stage, and fewer ER-positive tumors, and at younger ages, a pattern strikingly similar to that observed among U.S. black women. These data suggest that rather than being race-specific, differences in breast cancer are due to poverty; in the United States, being black may be a surrogate for being poor.
- Obesity is the second leading cause of cancer in the United States, second only to tobacco, and rates of obesity are continuing to increase. There is a correlation between high body mass index (BMI) and higher stage at cancer diagnosis. Also, among women diagnosed with premenopausal breast cancer, a BMI of greater than 30 at diagnosis is a risk factor for death from breast cancer. It is also important to note that high BMI correlates with low socioeconomic status. The fact that poor girls reach a weight of 100 pounds earlier than middle-class girls and begin menstruating earlier may play a role. Thus, diet, including the diets of pregnant mothers, may be important for determining cancer risk.
- There are no racial differences in breast cancer survival after adjusting for mammography screening, tumor characteristics, biologic markers, treatment, comorbidity, and demographics. However, black women are more likely to have worse biological markers and comorbidities and are less likely to receive high-quality screening.
- Numerous pattern-of-care studies have demonstrated that minorities and the poor are less likely to receive appropriate adjuvant chemotherapy, hormonal therapy, surgery, and radiation, and more likely to experience delays in treatment and dose reductions in chemotherapy. Differences in patterns of care by race have been documented for prostate, colon, breast, and lung cancer. Obesity and education, which correlate with socioeconomic status, can also influence the quality of chemotherapy. People who are overweight or obese, as well as those who have less than a high school education, are less likely to receive an appropriate dose of chemotherapy.
- A study was done comparing breast cancer mortality rates of black women living in Atlanta with those of black women who were retired from the military or whose spouses were military retirees. There are many social and cultural differences between these two groups of black women—those who were associated with the military had retirement income and health insurance. They were also more physically fit and interacted with whites and other racial groups while living on military bases. From 1993 to 1997, 561 black women died of breast cancer in Atlanta. If these women had had the same risk of death from breast cancer as black women in the military hospital system, 231 of these women would not have died.
- The reasons underlying health disparities are not fully understood, but studies suggest they may be due to cultural differences in acceptance of therapy, disparities in comorbid disease that make aggressive therapy inappropriate, lack of convenient access to therapy, and discrimination based on race and socioeconomic status. Rather than being concerned about race, society should focus on making sure that all human beings receive proper care.

DR. FRANCESCA GANY:

DECREASING CANCER DISPARITIES

Background

Dr. Francesca Gany is the founder and Director of the Center for Immigrant Health at the New York University (NYU) School of Medicine and the NYU Cancer Institute Cancer Outreach, Outcomes and Research for Equity Center. Dr. Gany is also Director of the Health Promotion, Disease Prevention, and Human Migration concentration in the NYU Global Masters of Public Health program. She has served as Principal Investigator on a number of pioneering immigrant health projects in the areas of cancer, language access and cultural competence, technology and immigrant health, insurance and access, tuberculosis, and cardiovascular disease. Her research has led to the development of long-term policy and programmatic changes in immigrant health. She has published and lectured widely on immigrant health issues and has also facilitated the dissemination of model projects nationally.

Key Points

- The NYU School of Medicine Center for Immigrant Health was founded in 1989 to decrease healthcare disparities and bridge immigrant communities with the healthcare system. The Center is a network of community members, community-based organizations, providers, researchers, facilitators, administrators, and program and policy developers. This diverse group of interested individuals facilitates the delivery of linguistically, culturally, and epidemiologically sensitive healthcare services to newcomer populations.
- Several years ago, with funding from NCI, the Center for Immigrant Health created the Cancer Awareness Network for Immigrant Minority Populations (CANIMP). This community-based participatory approach to addressing cancer health disparities comprised a cadre of minority scientists.
- CANIMP has since developed into the Cancer Outreach, Outcomes, and Research for Equity (CORE) Center. The CORE Center addresses disparities in cancer prevention, detection, treatment, and survivorship among immigrant and minority communities in New York City. The CORE Center conducts extensive community-based participatory education, screening, clinical care, research, and training programs to overcome barriers to care and bring evidence-based cancer interventions to medically underserved communities.
- All of the CORE Center's programs inform policy development. The Cancer Care Access, Retention and Quality program addresses socioeconomic and legal barriers to care. The program focuses on patient-provider communication and cultural responsiveness of the healthcare system. The CORE Center is committed to training and addresses cost-effectiveness as part of its research program, as cost-effectiveness generally drives policy.
- The CORE Center's partners participate in the design of research, analysis of results, and dissemination of findings back to the community. Some key partners include the Chinese American Planning Council, the South Asian Council for Social Services, the Caribbean Women's Health Association, and the Haitian Women's Program.
- The U.S. minority population is over 100 million people, or about 1 in 3 residents. Hispanics are the largest minority group, with 44 million persons; followed by blacks, with 40 million; and Asians, with 14 million. There are 32.5 million foreign-born individuals in the U.S., comprising 11.5 percent of the total population. For these individuals, there are higher incidence and mortality rates for many cancers, as well as decreased access to treatment and survivorship services.
- Minorities face social and economic barriers to treatment adherence, including inadequate housing; lack of education; unemployment; lack of childcare, transportation, and insurance; and inadequate nutrition. In addition to these barriers, immigrants face legal and language barriers, enjoy less social

support, and have other economic, personal, cultural, and family concerns that might make medical care a lower priority.

- Only a limited number of studies address interventions related to social and economic barriers to treatment adherence. A study by Guidry and colleagues found that Hispanics faced significant cost-related barriers to treatment. Formenti et al., found that immigrant Latinas with cervical cancer faced practical barriers to radiotherapy and that addressing these barriers improved rates of treatment completion.
- In response to the limited number of tested interventions available, the CORE Center developed the Integrated Cancer Care and Services Access Network (ICCAN), which is a needs assessment-based intervention. This intervention specifically targets social and economic barriers that prevent cancer treatment completion. The target populations are heterogeneous, underserved, immigrant minority groups who have low treatment adherence and experience a variety of cancers. ICCAN is a multisite program with 10 facilities in New York City.
- The key to the ICCAN intervention program is an access facilitator who assesses needs and synchronizes an individualized set of transdisciplinary services for each patient. These services include financial, transportation, food, and legal services assistance, in addition to childcare and referrals to cancer support organizations. As soon as needs are identified, ICCAN facilitators follow up with patients using a case management tool and actively link them with a specialist ICCAN team member/agency.
- ICCAN serves over 850 patients each year. Of these, 70 percent are female, 64 percent prefer a language other than English for healthcare, 62 percent have Medicaid or are covered by Medicaid for emergency care only, 76 percent did not complete high school, and 36 percent have been in the U.S. for less than five years (the cutoff for legal permanent residence to receive health insurance). More than half of patients reported that financial need prevented them from receiving proper care.
- The demographic and cancer characteristics and cancer-related needs differ among the population groups served by ICCAN, providing evidence for the need to disaggregate cancer data. The largest immigrant groups in New York City are from China, Mexico, and the Dominican Republic. Chinese were found to be the most vulnerable immigrant group (i.e., more recently immigrated, less likely to be documented, lower rates of insurance coverage, poorer access to social workers, more in need of financial assistance, and more likely to miss appointments).
- A retrospective sample of ICCAN patients was questioned regarding appointment keeping and quality of life. Of those surveyed, 78 percent reported that the program helped them attend appointments and 76 percent reported that it helped to reduce worry.
- Interpretation difficulties and errors can affect all stages of cancer care. Studies show that linguistic challenges can result in misdiagnoses, diagnostic test misuse, and poor understanding of treatments. In cancer care, communication challenges are amplified—consultations require transmission of complex and sometimes distressing information. Language barriers have a significant impact on cancer outcomes.
- Fostering an environment that encourages optimal communication is imperative. Recognizing this, the United Kingdom National Health Service recommended that the ability to communicate effectively be a precondition of qualification for all cancer care providers.
- In the U.S., many individuals have limited English proficiency (LEP)—defined by the census as a limited (i.e., less than “very well”) ability to understand, speak, read, and write in English. Almost 20 percent of immigrants in many cities are LEP. Over 45 million people speak a language other than English at home and over 175 different languages are spoken in the United States.
- In New York City, 25 percent of the population have limited English ability; however, rates among ethnic minority groups are much higher—70 percent of the Chinese population, 65 percent of the Russian population, and 50 percent of the Spanish population are LEP.

- Bilingual staff members, patients' family members, or volunteers—including volunteers who were physicians in their home country—may seem like adequate choices to be medical interpreters; however, none of these people are trained in medical interpretation, which often proves to be problematic.
- The Center for Immigrant Health conducted a study comparing errors made by trained and untrained interpreters using standardized, comparable medical content and interpreter training/assessment standards. Trained interpreters were 70 percent less likely than untrained interpreters to make clinically significant errors. Untrained interpreters were far more likely to use imprecise vocabulary: 7 percent of trained and 36 percent of untrained interpreters had less than 40 percent vocabulary precision.
- Examples of untrained interpreters' errors were provided. In one instance, a doctor stated, "The results were positive, which means that you carry the gene that puts you at risk for developing breast cancer." The interpreter simply told the patient, "The results were correct." In another example, the doctor said, "One important thing that you have going for you is the fact that the cancer has probably been caught early." The interpreter told the patient, "One important thing is the fact that the cancer is working quickly in your body."
- The Center tested the United Nation's style of interpretation, Remote Simultaneous Medical Interpreting System (RSMI), in the healthcare system. RSMI was associated with significantly fewer errors when compared with usual and customary modes of interpretation. Analyses of Spanish-language interpretation found that RSMI was 30 percent faster than the next fastest mode of interpretation (ad hoc) and twice as fast as over-the-phone consecutive interpretation.
- In a randomized, controlled trial of 868 patients, RSMI was associated with a higher referral rate for colonoscopy screening compared with usual and customary methods of interpreting. With RSMI, instructions were given more effectively in complicated clinical encounters and patient satisfaction was higher. RSMI provides better communication between patient and provider and can lead to better outcomes in terms of reduced error rates, better instruction giving, and improved treatment adherence.
- In order to address cancer health disparities, the economic, logistic, and linguistic barriers to education, screening, care and survivorship services, and participation in research must be eliminated.

DR. DANIEL PETEREIT

A MULTIFACETED APPROACH TO LOWER CANCER MORTALITY RATES AMONG AMERICAN INDIANS

Background

Daniel Petereit, M.D., is a radiation oncologist at John T. Vucurevich Regional Cancer Care Institute in Rapid City, South Dakota. He is also an associate professor at the University of Wisconsin School of Medicine and Public Health and the University of South Dakota Medical School. His clinical expertise is in prostate cancer, gynecologic cancers, brachytherapy, intensity modulated radiation therapy (IMRT), clinical trials, and cancer disparities. In 2002, Dr. Petereit was awarded NIH funding to launch Walking Forward, a Cancer Disparity Research Partnership that aims to reduce severe cancer disparities among American Indians in western South Dakota; funding for this program was recently renewed. Walking Forward is based in Rapid City Regional Hospital's community cancer center and serves four communities of Lakota Sioux American Indians. As Principal Investigator of this program, Dr. Petereit leads a 14-person team that assesses barriers to cancer screening, early detection, and treatment, and promotes patient navigation and access to clinical trials. It is hoped that the lessons learned in serving disparate communities of western South Dakota may also be applicable to other underserved populations in the world.

Key Points

- American Indians are the only racial/ethnic group that did not experience a decline in cancer mortality from 1995 to 2004. Northern Plains American Indians have a 30 percent higher cancer mortality rate compared with the overall U.S. population.
- Screening rates for breast, cervical, colorectal, and prostate cancers are significantly lower among American Indians than among the overall U.S. population. As a result, American Indians are more likely to be diagnosed with advanced stages of cancer and, thus, have higher rates of cancer mortality. For cancers for which effective screening tests exist, the collective mortality rate among Northern Plains American Indians is 80 percent higher than the mortality rates among whites.
- Walking Forward was established to address these disparities through an assessment of barriers to early cancer detection, a comprehensive patient navigation program, and recruitment to clinical trials. The program was funded in 2002 by the NCI Cancer Disparity Research Partnership program and recently received renewed funding.
- Walking Forward administered surveys to American Indians treated at community cancer centers and more than 1,000 American Indian community members to identify specific barriers to early cancer detection and treatment, as well attitudes and beliefs about cancer treatment and care. Findings from these surveys identified several barriers to cancer screening and treatment. A doctor's or nurse's recommendation was the primary factor in respondents' decisions to be screened for cancer; however, few had received a recommendation for screening. A large number of survey respondents also identified distance and lack of transportation as one of the most common barriers to accessing treatment and care (the closest cancer center is a median of 140 miles away from the reservations). The costs of transportation, food, and lodging were also identified as barriers.
- Survey data also revealed that American Indians had higher levels of mistrust and lower levels of satisfaction with the healthcare system compared with the overall U.S. population. American Indians were also found to have less screening knowledge and more negative attitudes toward cancer care compared with the overall U.S. population.
- Walking Forward's patient navigation program was established to better understand and address the barriers to timely and effective cancer diagnosis and treatment. The patient navigation program is located on the reservations, where Walking Forward staff members promote education, outreach, and networking, as well as assess barriers to screening and early detection. A patient navigation program is also located at Rapid City Regional Hospital's community cancer center, where Walking Forward staff members assist American Indians with their cancer treatment.
- Walking Forward's patient navigation program has had several successes to date. Data show increased patient enrollment to clinical trials and increased adherence to prescribed cancer treatment regimens among those who participated in the patient navigation program compared with American Indian patients who did not. In addition, a preliminary analysis of 37 patients who participated in the navigation program showed an improvement in satisfaction as they were going through their cancer treatment. Perhaps the most important effect of the patient navigation program is that it fostered trust and built relationships that serve as the foundation of the Walking Forward program as a whole.
- In an attempt to lessen the burden experienced by those who need to travel long distances to be treated at cancer centers, Walking Forward, in collaboration with the University of Wisconsin, developed clinical trials studying the use of IMRT to treat prostate cancer and brachytherapy to treat breast cancer. IMRT can shorten treatment duration from eight weeks to four weeks; brachytherapy can shorten treatment duration from six weeks to five days. To date, approximately 50 American Indians with prostate cancer and 32 American Indians with breast cancer have enrolled in these trials.
- Anecdotal accounts suggest that American Indians have higher rates of severe skin reactions to radiation treatment than whites. Walking Forward conducted an exploratory pilot study to determine whether a variation in the *ATM* gene, known to be responsible for DNA repair, may cause severe skin

reaction and other radiation-related toxicities. Using blood samples drawn from 100 American Indians and 100 whites, researchers are analyzing the *ATM* gene and correlating findings to radiation toxicities. The eventual goal is to tailor therapy based on a patient's molecular profile. For example, if a breast cancer patient is found to have a gene variant that predisposes her to severe skin reactions, she would not be a candidate for one of the studies wherein a high-intensity course of radiation is used.

- Walking Forward also completed an intervention aimed at increasing screening rates among American Indians for breast, cervical, colorectal, and prostate cancers. Levels of knowledge regarding screening among 400 American Indians were measured before and after participation in educational workshops. Data revealed that screening knowledge increased after the 60-90 minute workshops. Postworkshop follow-up data from 125 participants showed increased screening among participants for breast, cervical, and prostate cancers, but no change in screening rates for colorectal cancer. Walking Forward is currently following up with the remaining participants.
- To date, more than 2,000 American Indians have participated in a component of Walking Forward. The rate of accrual to Walking Forward studies is approximately 10 percent, significantly higher than the participation rates of less than 1 percent that have been observed among American Indians in other studies.
- Walking Forward is partnering with the American Cancer Society (ACS) to increase its presence in American Indian communities. Cancer screening coordinators will be housed within Indian Health Service clinics to promote screening, coordinate screening events, and help follow up on abnormal results. Community navigators are also present on the reservations to promote screening and help people determine whether or not they should be screened. Once an individual is diagnosed with cancer, he/she will be helped by a cancer navigator in the hospital setting.
- Walking Forward's future goals include expanding its patient navigation program, expanding the scope of its clinical trials, and identifying genetic factors that could be predictive of adverse responses to radiation.

DR. JEAN FORD:

CANCER CONTROL FOR AN AGING AND ETHNICALLY DIVERSE POPULATION

Background

Jean Ford, M.D., is associate professor in the Department of Epidemiology at the Johns Hopkins Bloomberg School of Public Health. Dr. Ford's primary research interest is in understanding pathways that contribute to cancer-related racial/ethnic and socioeconomic disparities. He directs community-oriented projects designed to elucidate risk factors that contribute to the disproportionate cancer burden in low-income minority communities in Baltimore City and evaluates the efficacy of intervention strategies to improve preventive care for individuals at risk for or diagnosed with cancer. His active studies include Cancer Risk Assessment in Baltimore (CRAB), a cross-sectional study of risk factors in a predominantly African-American sample of Baltimore City Residents, and Improving Participation in Oncology Research Trials (IMPORT), an investigation of determinants of racial disparities in participation in cancer therapeutic trials. He was recently awarded a cooperative agreement from the Center for Medicare and Medicaid Services (CMS) to conduct a population-based randomized controlled trial to test the efficacy of a behavioral intervention to improve adherence to cancer screening and treatment among African-American Medicare beneficiaries. He also directs low-cost breast, colon, and prostate cancer screening programs targeting low-income Baltimore City residents.

Key Points

- The Partnership for Healthy Seniors, based in Baltimore, Maryland, is one of six sites funded by the CMS Cancer Prevention and Treatment Demonstration for Racial and Ethnic Minorities. The goal of the Partnership is to reduce disparities in cancer deaths among racial and ethnic minorities by using community health navigators to improve the coordination of cancer screening services, reduce barriers to cancer care, and increase clinical trial participation.
- The Partnership is currently studying the impact of community health navigators through two randomized, controlled clinical trials. One of the trials is comparing the efficacy of educational materials versus educational materials plus patient navigation services in promoting adherence to cancer screening. Eligible participants must be African American, at least 65 years old, enrolled in Medicare Parts A or B, not currently in hospice, and not currently diagnosed with cancer.
- After responding to the Cancer Screening Assessment (CSA), a baseline questionnaire, participants are randomized to two groups. The first group receives general information about cancer and Medicare-covered services, as well as instructions to discuss the information with their primary care doctors. The second group receives the same information as the first group, as well as tailored support services from a health navigator who guides them through their diagnosis, treatment, and survivorship.
- In recruiting study participants, the Partnership used three different sampling strategies: population-based sampling, population-based sampling in combination with convenience-based sampling, and enhanced population-based sampling. The third recruitment strategy has proved most successful. In conducting enhanced population-based sampling, the Partnership starts by identifying potential participants through the Medicare roster. From there, potential participants are sent letters accompanied by culturally appropriate materials. They are subsequently contacted and an interviewer then is dispatched to discuss the study face-to-face.
- Different sampling strategies revealed important information about study participants. For instance, convenience-based sampling, which was conducted at senior centers and other venues where seniors congregate, reached a population that had, on average, lower income and less education than those recruited through population-based sampling. They were also more likely to live alone. Researchers thus noted that the settings in which participants are recruited have implications for the external validity of the study's findings.
- Several observations have been made to date. First, more than 80 percent of the population recruited are overweight or obese. Second, more than 70 percent identify as having smoked 100 or more cigarettes in their lifetime, with approximately 20 percent currently smoking daily. Third, almost 70 percent identify as having three or more comorbidities and taking six or more medications. Researchers note that these risk factors must be taken into account when interpreting study data as they have the potential to impact the effect of the interventions.
- Preliminary data from the study were also analyzed to determine whether there was an association between cognitive functioning and colorectal cancer screening. Cognitive impairment is thought to affect approximately 22 percent of people ages 71 and older. Cognitive impairment can result in an accelerated progression to dementia, decreased quality of life, reduced medication and treatment adherence, and reduced ability to make decisions.
- The Partnership assessed cognitive functioning in 900 participants using the Mini-Cog tool, a three-item recall and clock-drawing test. The Mini-Cog is relatively uninfluenced by level of education or language variations, and has been validated in multiple ethnic groups. The impact of participants' Mini-Cog scores on colorectal endoscopy rates, along with other variables, was analyzed.
- It was found that cognitive functioning was impaired in 42 percent of participants, more than previously perceived. Among those who were found to be cognitively impaired, 72 percent reported

having been screened for colorectal cancer within the previous 10 years, compared with 82 percent of those who were not found to be cognitively impaired.

- A number of other factors were associated with adherence to colorectal screening, including gender, income, socioeconomic status, education level, a primary care relationship, and social support. After controlling for these variables, those who were found to be cognitively impaired were approximately 34 percent less likely to report having been screened for colorectal cancer than those who were not cognitively impaired.
- Researchers were unable to distinguish cognitive impairment from poor literacy. The Partnership's next step is to assess literacy and numeracy in relation to cognitive functioning using a more detailed instrument.

DISCUSSION AND CONCLUDING COMMENTS:

PANEL I

Key Points

- Hepatitis B is one of the principal causes of liver cancer; among Asians, 80 percent of liver cancer cases are attributable to hepatitis B infection. There is an effective vaccine against hepatitis B that is delivered at birth in the United States. In many states, hepatitis B vaccination is required prior to school entry. This is an effective mode of utilizing vaccination as primary prevention; however, foreign-born adults are often not vaccinated and may have been previously exposed to the virus. Because of widespread vaccination among U.S.-born populations, liver cancer is not generally looked for in the clinical setting. In addition, language barriers often prevent effective communication between non-English-speaking patients and providers regarding testing for hepatitis B.
- It was suggested that screening for liver cancer should be conducted among APIs due to their low rates of hepatitis B vaccination, despite the fact that a survival benefit has not yet been shown for this type of screening. However, it was also pointed out that cancer screening is not always beneficial. In the 1960s, it was shown that using chest x-rays to screen smokers for lung cancer was associated with higher rather than lower risk of death. In addition, screening one-year-old children for neuroblastoma increases risk of death.
- Current census classifications do not accurately capture information on all Asian-American subpopulations. Many Asian Americans, such as those from the Middle East, are still counted in the census as white.
- The recent recommendations of the U.S. Preventive Services Task Force regarding breast cancer screening guidelines were discussed. Concern was expressed that delaying regular mammography screening until age 50 as recommended by the Task Force would not be appropriate for women from minority and socioeconomically disadvantaged populations that tend to develop cancer earlier. It is recognized that there is a distribution of risk factors and biological features among population subsets with the same diagnosis; thus, the same public health interventions may not be appropriate for all populations. For example, it may be appropriate for African-American men to begin being screened for prostate cancer earlier than the general population. However, it is sometimes difficult to make definitive recommendations for various populations because they are inadequately represented in clinical trials. It was also pointed out that individuals with inadequate access to care tend to be screened less often than recommended (e.g., if the recommended interval for mammography screening is two years, women with insufficient access to healthcare may go for screening every three to four years).
- Dr. Brawley stated that all women should have access to annual screening mammography beginning at age 40, but pointed out that mammography is an imperfect test and emphasized the need for an improved screening technique. Although mammography is useful, it is important that its benefits not

be exaggerated. For example, mammography is not as effective for women with dense breasts; it is possible that breast self-awareness and self-surveillance may be more effective than mammography for detection of breast cancer in women with dense breast tissue.

- Human papilloma virus (HPV) infection progresses significantly faster in women also infected with human immunodeficiency virus (HIV). It may be appropriate to use alternative approaches to screen HIV-positive women for cervical cancer.
- There is some evidence that colorectal cancer is becoming more common among young people. This may be due to dietary factors. However, it is unknown whether screening this population would be beneficial or cost-effective.
- Adoption of healthcare reform initiatives currently being discussed will help address health disparities in the United States but will not eliminate them. Disparities persist in countries that provide universal access to healthcare, but these disparities are generally less than those seen in the U.S. It was pointed out that in addition to improving access, it is important to improve the quality of care received by underserved populations. Educational and patient navigation programs will likely be needed to foster trust and encourage underserved populations to utilize available care. Reform may actually further marginalize immigrant populations by shifting resources away from services for this population.
- The Gouverneur Diagnostic and Treatment Center on the Lower East Side in New York City, which is part of the New York City Health and Hospitals Corporation, began using RSMI as part of a pilot study. Because of the success of this program, the approach is now being used by several facilities in New York City and other locations. The mechanisms used to pay for remote simultaneous translation are the same as those used to pay for other translation services: in some states, Medicare, Medicaid, and insurance companies provide fee-for-service funding, while in other cases translation services are paid for through the general hospital operating budget. However, in many cases, provision of translation services is an unfunded mandate. RSMI is more efficient than traditional translation services and is thus less expensive overall.
- Interpreters should be trained in medical interpreting; being bilingual is not enough. It is important that interpreters be skilled communicators and culturally sensitive. Many people think that asking a physician from the patient's home country to interpret would be an optimal approach, but pilot studies have shown that the physicians tend to become involved in the interviews as physicians rather than interpreters. There are a number of organizations in the United States that are skilled at training interpreters.
- The Walking Forward program recruited community navigators to help reach out to the Native American community. Each reservation already had a community health representative—a layperson people can talk to if they have questions related to health or healthcare. The Walking Forward community navigation program was modeled on this approach. Community navigators live in the community and were recruited through Lakota newspapers; all of the current navigators have college degrees and have previously served as community health representatives.
- The efficacy of shorter-duration radiation therapy is being investigated in clinical trials. Phase II clinical trial data suggest that shorter radiation schedules can achieve cure rates similar to traditional radiation therapy. The Radiation Therapy Oncology Group is currently conducting a Phase III trial focused on shorter radiation schedules.
- The Partnership for Healthy Seniors study found that approximately one-third of participants aged 65 to 74 exhibited mild cognitive impairment. This prevalence was higher than expected based on published reports. These observations have public health implications given the fact that the U.S. population is aging.
- In every clinical interaction, clinicians should strive to provide the best possible care to the individual being treated. They should take culture, race, and socioeconomic status into account, but the focus should be on utilizing the information available to provide the best care. In attempting to learn why

treatments differ in efficacy among populations, it would be more beneficial to focus on molecular differences in cancer and drug metabolism rather than on race.

- Improving access to high-quality health care, including preventive care, is the most important thing that can be done to address cancer health disparities.
- Evidence-based interventions, such as navigation and facilitation, should be used to help disadvantaged patients achieve better outcomes. Effective patient-provider communication is also important as it can help reduce errors, improve safety, and increase adherence.
- NCI-funded research programs have an important impact on the community level and can effectively reach vulnerable populations. Effective patient navigation programs allow researchers to build trusting relationships with communities, creating an infrastructure in which to conduct meaningful research.
- There is evidence that community health workers and patient navigators can be beneficial, although there are still questions about the long-term cost-effectiveness of using navigators. Consideration should be given to training designated caregivers to serve in a navigator role. One study found that 39 percent of Medicare beneficiaries are accompanied by a caregiver or family member to doctor appointments and that these patients tend to report higher satisfaction with their interaction with the provider and greater understanding of what was discussed during the appointment. Utilizing caregivers as navigators may be a cost-effective way to improve patients' experiences.

PUBLIC COMMENT

Key Points

Anne Lubenow, Special Assistant to the NCI Director, provided an update regarding NCI's community outreach efforts.

- NCI made the decision more than a year ago to discontinue the Cancer Information Service Partnership Program (CIS) as it has been defined for almost three decades. This was not a decision that was made hastily. While NCI's commitment to disseminating cancer information, particularly in underserved communities, has never been limited to one program, it was recognized that CIS had become a familiar partner to many in the community.
- In July 2009, NCI announced plans to incorporate its community outreach and cancer information dissemination activities as key components in all of the Institute's community-based research programs. This integration will create an enhanced National Outreach Network, ensuring that all communities, particularly those that are underserved, have continued access to the work of the NCI and critical cancer information. NCI believes effective dissemination of cancer information, particularly to diverse populations, is a responsibility that should be met by all of its community-based research programs. The community is best served by the full spectrum of resources and expertise of the NCI and these can only be brought to bear when community outreach is not an isolated activity, left to the responsibility of a single program.
- As a result, NCI will be expanding its community outreach capacity through several entities, including the Community Networks Program, the Minority Institutions/Cancer Center Partnerships program, the Patient Navigation Research Program, the Minority-based Community Clinical Oncology Program, the NCI Community Cancer Centers Program pilot, and the NCI Cancer Centers. These existing programs, all with proven track records in the community, will provide the foundation for the National Outreach Network. These efforts will ensure continued support of the community at the conclusion of the Cancer Information Service Partnership Program in January 2010 and will create greater cohesion between the community and the research mission of NCI.
- A comprehensive implementation plan for the National Outreach Network has been developed. NCI is utilizing American Recovery and Reinvestment Act (ARRA) funds to allow for the immediate

addition of Community Health Educators to existing projects in the Community Networks Program, the Minority Institutions/Cancer Center Partnerships program, and sites involved in the NCI Community Cancer Centers Program. These Community Health Educators will assist patients in underserved communities as they receive, process, and understand health-related information and services.

- In fiscal year 2010, NCI will provide funding to those Network programs not supported with ARRA supplements to further build and reinforce the National Outreach Network. Once implemented, this network of community outreach activities will represent multiple sites across the United States and ensure coverage to some of our most vulnerable populations. This approach will allow for a seamless transition between the end of the CIS Partnership Program and the full scale-up of the National Outreach Network.
- Lastly, NCI will be incorporating a Community Outreach Core into each of its community-based research initiatives as they are reissued. These new cores will provide continued staff and resources for outreach, education, and dissemination to NCI-funded research programs working in the community and fully integrate and sustain the Community Health Educators in the National Outreach Network. This approach will enable these programs to perform their unique research mission as well as support NCI and the community in meeting cancer control needs. It is anticipated that the Community Networks Program and the Minority Institution/Cancer Center Partnership awards with the new Outreach Cores will be made in early 2010.
- Coordinating the Institute's outreach activities across its community-based research programs will enhance its ability to work with the community to identify, develop, and disseminate tailored, culturally sensitive, evidence-based information and materials that are responsive to community needs and expectations. The Institute will also be better informed of the educational needs of communities and better positioned to help address them. It is hoped that this approach will more effectively engage communities in NCI research and build capacity in those communities for ongoing information dissemination.

PANEL II

DR. TIMOTHY REBBECK:

A MULTILEVEL MOLECULAR EPIDEMIOLOGY APPROACH

Background

Dr. Timothy Rebbeck is professor of epidemiology, Senior Scholar in the Center for Clinical Epidemiology and Statistics, Director of the Center for Genetics and Complex Traits, Director of the Center for Population Health and Health Disparities, Director of the Laboratory for Molecular Epidemiology, and Associate Director for Population Science at the Abramson Cancer Center of the University of Pennsylvania. Dr. Rebbeck's research focuses on the genetic and molecular epidemiology of cancer. He directs multiple molecular epidemiologic studies and international consortia that aim to identify and characterize genes potentially involved in cancer etiology and to describe the relationship of allelic variation with biochemical or physiological traits, cancer occurrences, and cancer outcomes. Dr. Rebbeck's research uses a multidisciplinary approach that combines methods from epidemiology, statistics, molecular biology, and classical genetics. Dr. Rebbeck has identified novel genes associated with prostate cancer, including those involved in hormone metabolism; characterized interactions between hormone exposures and hormone metabolism genotypes in both breast and endometrial cancer; and discovered novel pigmentation genes in melanoma. He also showed that preventive surgery reduces breast and ovarian cancer risk by 80-90 percent among BRCA1/2 mutation carriers and significantly improves survival of these patients. This work has changed the clinical management of hereditary breast cancer risk prediction and prevention. He leads a transdisciplinary health disparities research program that has

shown how susceptibility genes, screening, neighborhood factors, and individual environments jointly contribute to prostate cancer disparities between black and white men.

Key Points

- U.S. Census race categories have evolved over time and have been heavily influenced by politics and other social trends. As such, they may not be the most useful categorization paradigm when studying health disparities. Optimally, researchers would identify and use personalized metrics of risk rather than using these categories.
- The many factors that contribute to health disparities can be categorized as either differences or inequities. Differences include things such as genetics, race/ethnicity, environment, and biology/physiology, while inequities include factors such as discrimination, segregation, and access to care. Depending on the nature of these factors, information about them might be used differently. For example, information about genetics and race/ethnicity might be useful for risk stratification but would probably not be amenable to intervention since these factors are unchangeable. On the other hand, information about environment could be useful for both risk stratification and intervention, while biology/physiology, discrimination, segregation, and disparities in access would be appropriate targets for intervention.
- Traditionally, health disparities are studied by looking for associations between self-reported race/ethnicity and health outcomes; however, this approach can be problematic. A new framework is needed that takes into account the many complex factors that can contribute to disparities. One proposed framework reflects the relationships between self-identified race/ethnicity, culture, environment, phenotype, ancestry, genomic variation, disease-causative genetic variation, and disease outcomes. The correlations and interplay between many of these factors have important implications for disparities.
- Ancestry informative markers can be used to assess an individual's ancestry. Using mitochondrial ancestry informative markers, it was determined that individuals in the Americas who self-identify as being of African descent vary significantly with regard to the region of Africa from which their ancestors came. People who self-identify as African American also have varying levels of European and Native American ancestry. This illustrates the genetic variability that exists among people who would be grouped into the same census category.
- Analyses are being done to learn more about how individual-level risk factors—such as neighborhood, environment, and personal behavior—influence genetic susceptibility to cancer. For example, one study found that African Americans and European Americans who lived in mixed-race neighborhoods exhibited nearly identical rates of prostate cancer mortality. However, as the degree of racial segregation increases, prostate cancer mortality rates for African Americans increase dramatically while those for European Americans diminish. Neighborhood factors such as the level of racial segregation may correlate with differences in access to care and quality of available care.
- Several recent genome-wide association studies have evaluated genes potentially involved in prostate cancer susceptibility. Most of the genes identified confer very low risk of disease on their own, suggesting that in order for them to be clinically meaningful, they will need to be considered in combination with other genetic variants and/or environmental exposures. For example, the SCORE (Salvage Cryotherapy Registry Evaluation) study has found that several single nucleotide polymorphisms (SNPs) correlated with failure of prostate cancer treatment but only among individuals with particular education, income, or neighborhood characteristics (e.g., one SNP correlated with treatment failure only among those with no college education). These observations show that some genotypes have their effect only within certain environmental contexts. Characterization of these types of gene-context interactions could help identify individuals with a particular genotype who are at high risk for poor outcomes because of where they live, their education level, or their income status.

- In summary, improved metrics and approaches are needed to assess race and ethnicity. It is important to consider a variety of environmental contexts in which risk factors and biology may be acting. It may be necessary to develop interventions for specific population subgroups. Multilevel analyses that consider the joint effects of genotype, biological factors, individual risk factors, and area-level factors may be useful in this regard.

DR. MICHELLE VAN RYN:

THE CONTRIBUTION OF PROVIDER UNINTENDED BIAS TO RACIAL DISPARITIES IN CANCER CARE

Background

Dr. Michelle van Ryn is an associate professor in the Department of Family Medicine and Community Health at the University of Minnesota Medical School. She earned her Ph.D. and M.P.H. from the University of Michigan School of Public Health. Dr. van Ryn's research focuses broadly on social relationships and health in a social-structural context with special attention to factors that influence the effectiveness of provider-patient relationships, especially across race, gender, socioeconomic status, and other social position markers. Her work on the unintended contributions of providers to racial disparities in healthcare has been widely cited and has contributed to a large and growing branch of research on healthcare disparities. Dr. van Ryn is currently Principal Investigator on several studies, including a five-year study examining the contribution of medical school and individual student factors to racial bias among medical students, a study examining variations in patient-centered quality of cancer care, and a pilot test of a Web-based intervention intended to reduce the impact of implicit bias and improve provider decision making.

Key Points

- The benefits of cancer-related medical care may be greatest for low socioeconomic status (SES) and minority populations who have the greatest exposure to risk factors, the least health-protective resources, and, thus, greater healthcare needs. Unfortunately, the benefits of high-quality cancer care are inequitably distributed.
- Race differences in stage at diagnosis, comorbidity, insurance, site of care, and referral to a cancer specialist all contribute to treatment disparities.
- Black patients are less likely than white patients to receive optimal care associated with cancer prevention, including being informed of risk of cancer associated with family history and receiving diet and exercise counseling.
- Black patients are also less likely than whites to receive cancer screening. If screened, black patients more often experience failure of follow-up or unacceptable delays between screening results and diagnostic workup, even within the same care system and with the same insurance.
- Black patients are less likely than whites to receive a variety of cancer-related treatments. For example, black women with breast cancer have been found to have lower rates of lumpectomy than white women with similar clinical profiles. Additionally, black patients are less likely to have good symptom control and high-quality palliative care.
- In 1999, Congress asked the Institute of Medicine (IOM) to assess the extent of disparities in the types and quality of health services, explore factors that may contribute to inequalities in care, and recommend policies and practices to eliminate inequities. The IOM consistently found racial and ethnic disparities across a wide range of disease areas and clinical services. The National Healthcare Disparities Report—developed by the Agency for Healthcare Research and Quality—has found that, in many cases, disparities have widened since that time.

- The IOM panel identified three psychological processes that may play particularly important roles in physicians' "discriminatory patterns of healthcare": (1) prejudice or bias against minorities; (2) beliefs or stereotypes about the behavior or health of minorities; and (3) greater clinical uncertainty when interacting with minority patients.
- Racial bias refers to any differences in providers' judgment, behavior, or decisions that are due solely to patient race—it does not necessarily imply conscious, intentional bias. Prejudice involves different general feelings and attitudes toward a member of a group specifically because he/she is in that group; it has cognitive and affective (e.g., emotional reaction) components. Stereotypes are concepts that contain our beliefs and expectations regarding a social group, including traits and behaviors and causal theories about how given traits and behaviors are obtained. Stereotypes may be connected to or elicit an emotional reaction.
- Stereotypes serve the need for cognitive efficiency, so they are more likely to be activated and applied when individuals are tired, distracted, pressed for time, anxious, or cognitively busy.
- The terms "implicit," "unconscious," and "automatic" are closely related and refer to mental associations that are so well established they operate without awareness or intention. In contrast, individuals are fully aware of their explicit stereotypes. Implicit processes occur as part of human cognitive strategies that are largely adaptive.
- Blatant (explicit) forms of prejudice have declined dramatically over the past few decades, particularly among well-educated segments of the population. However, unconscious, unintentional (implicit) forms of prejudice are still pervasive, with 70 to 80 percent of white Americans, including white physicians, showing a significant implicit preference for whites over blacks. There are over 30 peer-reviewed studies showing that whites have strong, implicit negative associations with blacks and other non-white groups.
- Individuals are frequently unaware of activation of implicit prejudice and stereotypes and their impact on the individual's own perceptions, emotions, and behaviors. Implicit prejudice and stereotypes are activated more quickly and effortlessly than conscious cognition. Many cognitive processes result in confirmation of expectancies (i.e., we process information in ways that support our beliefs).
- Implicit bias can influence clinical decision making. In 2007, an experiment was conducted in which internal medicine and emergency medicine residents at four academic medical centers in Boston and Atlanta were randomly assigned to view a clinical vignette of a black or white patient presenting to the emergency department with an acute coronary syndrome. Explicit and implicit biases were assessed after medical residents responded to questions about the vignette. Physicians were consciously unbiased and reported no explicit preference for white versus black patients or differences in perceived cooperativeness. However, measures of implicit preferences showed the majority of medical residents had implicit biases favoring whites. Importantly, as physicians' pro-white implicit bias increased, so did the likelihood of treating white patients and not treating black patients with thrombolytic therapy.
- Provider bias can contribute to disparities in several connected ways. Implicit biases can influence providers' expectations of patients (e.g., adherence, follow-up), interpretation of patient symptoms and behavior, and behavior in the encounter. For example, in a random vignette study of receipt of highly active antiretroviral therapy (HAART), physicians rated black patients as more likely to be nonadherent to treatment. In a separate study, the same physicians were less likely to recommend HAART to patients they expected to be nonadherent.
- There is overwhelming evidence that information about others is attended to and interpreted through a cognitive "screen," or framework of beliefs. This cognitive framework guides attention and interpretation, which in turn can influence clinical decision making. A number of studies have found that observers assign different meaning to the same behavior depending on the race, class, or other group category of the person being observed. For example, mental health providers' diagnoses of a

videotaped adolescent varied significantly according to whether or not they were told the child had an alcoholic parent.

- Patients' race and other factors influence what physicians discuss with them. Blacks and low-income patients have been found to be less likely to receive information on treatment options and side effects or to have a discussion, get counseling, or receive recommendations regarding prevention (e.g., smoking, nutrition and exercise, screening).
- Four separate studies of patients with advanced illness found that black patients were less likely than their white counterparts to report that their providers discussed end-of-life care with them, despite their equal or stronger desire to have such a discussion.
- Implicit, but not explicit, measures of racial prejudice have been shown to predict higher rates of blinking and less visual contact. This is important because higher levels of visual contact reflect greater attraction, intimacy, and respect, while higher rates of blinking reflect more negative arousal and tension. A study examining the relationship between explicit and implicit bias on an interracial encounter showed that blacks were influenced by their white interaction partners' nonverbal behavior when assessing their partners' friendliness. Compared with whites, blacks had more negative impressions of the friendliness of their partner. Additionally, the impressions of white and black interaction partners were essentially uncorrelated (i.e., the reported perceptions of an interaction were often very different for the black participant compared with the white participant).
- Three other studies using different measures of subtle racial bias each found that whites' implicit racial bias scores predicted how positively they were perceived by black experimenters. The fact that explicit attitudes predict verbal behavior, while implicit attitudes predict nonverbal behavior, suggests that consciously egalitarian providers with negative implicit attitudes may be sending mixed messages in clinical encounters.
- In 2008, Lisa Cooper and colleagues examined the relationship between implicit bias and encounter characteristics among 39 physicians interacting with 213 black patients. The distribution of pro-white implicit bias in this physician group was similar to that in the general population, about 75 percent.
- Since patient behavior in clinical encounters is likely to be strongly influenced by physician behavior, modifications in either physician or patient behavior have the potential to create a beneficial positive feedback loop.
- Participatory decision making by providers is positively associated with patient satisfaction, self-disclosure, successful self-management, adherence, lower pain levels, and recovery. Trust in one's physician predicts utilization of preventive health services.
- Patient assertive behavior (active participation) increases the likelihood of full tumor staging among black and low-SES breast cancer patients, and also influences physicians to adopt a more patient-centered style of communication.
- Interventions targeting the impact of bias on decision making and encounter characteristics are a necessary component of a comprehensive approach to eliminating racial disparities in the cancer burden.

DR. YOLANDA PARTIDA:

LINGUISTICALLY DIVERSE COMMUNITIES AND CANCER: CREATING CAPABILITIES FOR SAFE, QUALITY HEALTHCARE

Background

Yolanda J. Partida, M.S.W., D.P.A., is Director of Hablamos Juntos and assistant adjunct professor at the University of California, San Francisco Fresno Center for Medical and Education Research. Hablamos Juntos (We Speak Together) was created in 2001 as a national initiative of the Robert Wood Johnson

Foundation. Dr. Partida has extensive experience in public/teaching and private hospital administration, public health administration, and private consulting. In these settings she has been responsible for overseeing a variety of personal and public health programs, developing community-level strategic plans, designing and conducting feasibility studies, and producing business case analyses. She has worked with and on behalf of many different groups of underserved populations, including the uninsured and the U.S.-Mexico border population, as well as the broader Latino community and communities of other ethnic minority groups. Dr. Partida holds a master's degree in social work and a doctorate in public administration with emphasis on public policy and health administration from the University of Southern California. She served as a member of the IOM Committee on Communication for Behavior Change in the 21st Century, which published *Speaking of Health: Assessing Health Communication Strategies for Diverse Populations*, and is currently on the IOM Roundtable on Health Literacy and Future of Nursing Committee.

Key Points

- Biological, genomic, and environmental factors must be considered when studying disparities, but it should be recognized that each of these factors on its own provides an incomplete picture of the circumstances that result in the unequal burden of sickness and disease.
- Psychosocial factors play a significant role in how patients and families respond to cancer diagnosis and approach decision making about treatment and supportive care. These factors influence how patients interact with healthcare providers and should be taken into account when developing ways to improve patient-provider communication.
- The U.S. immigrant population is growing quickly. Recent immigration trends have significantly increased the number of people who speak a language other than English in the home from 38 percent in the 1980s to 47 percent in the 1990s. The number of languages spoken in the United States is higher than that in Europe, and the U.S. is more linguistically diverse now than at any time since the early 1900s.
- Language diversity varies by region and community. Ancestral cultural and linguistic practices continue to play important roles in some communities and families, even when many generations have passed since the most recent immigrant arrived in the United States.
- Language barriers contribute to difficulty navigating the healthcare system (e.g., finding physicians, making appointments), confusion and inability to communicate, low patient satisfaction, and increased risk of provider inattention and receipt of low-quality care.
- Language barriers also create challenges for healthcare providers, making it more difficult for them to make accurate diagnoses, provide important health information, perform informed consent responsibilities for clinical trials, and engage patients in their care. Patient safety and quality of care depend on effective communication.
- The Robert Wood Johnson Foundation sponsored an initiative called *Hablamos Juntos*, which focuses on identification of practical, affordable solutions to eliminate language barriers and increase quality of care for Latino patients. Components of the initiative include increasing availability of language services/interpreters, developing health-related materials in non-English languages, and developing graphic-based signage. During the first phase of the effort, \$10 million was invested in demonstration projects at 10 sites, including hospitals, community-based organizations, education centers, and health plans. The second phase of the study entailed an in-depth study of translation, translation quality, and the implications of translation-related issues. The study of translation was initiated because it was discovered that many translated materials considered to be of high quality were not easily understood by the target audience. Conclusions drawn from these studies include: culture and language are inextricably linked, health literacy is an important consideration, interpreters/translators are necessary but not sufficient to address language and cultural barriers, and there is need for robust national investments and collaboration.

- Translations that attempt to retain the original language structure are sometimes unintelligible to the reader. This is one reason it is important to use trained translators and interpreters.
- Translators need to go beyond exchanging words between patients and providers; they need to help ensure that patients understand what is being said. Trained translators are most qualified to do this.
- Mandates to provide translation services are increasing. Unfortunately, many organizations do not draw on what is already known about effective and efficient ways to provide these services.
- Development of linguistic competencies within the U.S. is important in many domains, including national security, economic competitiveness, and social well-being.
- Universal healthcare symbols are one potential way to improve patient interactions with the healthcare system; however, more fundamental changes are also needed. Minority populations must play a larger role in the leadership of healthcare organizations and the nation.
- The field of language services should be further developed. Interpreters and translated materials are essential services for overcoming language barriers to healthcare, but current practice is woefully inadequate and may actually increase risks for poor health outcomes by allowing health professionals to believe effective communication is taking place.
- Incentives should be created for industry to build capacity to care for culturally and linguistically diverse communities. Regional collaborative research networks should be created to accelerate the development and dissemination of strategies for building competencies of healthcare organizations to meet the communication needs of patients with limited English proficiency. National investment is also needed to support diversification of the healthcare workforce.

DISCUSSION AND CONCLUDING COMMENTS:

PANEL II

Key Points

- The factors that contribute to health disparities are numerous and diverse. Some of these factors are modifiable while others (e.g., genetics) may inform risk stratification but be less amenable to intervention. It is important to consider what can be gained from learning about particular factors rather than viewing all contributors as equal.
- In general, healthcare providers are motivated to treat their patients as individuals, but features of modern healthcare settings (e.g., limited time with patients) often drive physicians and other providers to rely on implicit bias. Certain skills may reduce the likelihood that implicit bias will occur; these include perspective-taking skills, emotion regulation, and self-awareness. Providers can take an implicit association test to improve their self-awareness. It is important that conversations about implicit bias take place without hostility or blame. Many people have strong reactions to being told that they are biased, and these reactions can be counterproductive. One approach is to allow people to begin exploring the idea of implicit bias privately using a Web-based program. Another approach is to broach the subject using an example that illustrates the danger of relying on positive stereotypes (e.g., assuming that a young woman is knowledgeable about diabetes because her father is a gastroenterologist). Providers should understand that all patients must be treated as individuals and should be given the resources and skills to help them behave in ways that are consistent with their values.
- Racial/ethnic concordance between patients and providers may alleviate some interracial anxiety and bias, but does not solve the problem. Implicit bias can occur even when patient and provider are of the same race/ethnicity, in part because there may be differences in class and/or socioeconomic status. The healthcare workforce should reflect the population being served; diversity within the workforce is important for ensuring that multiple points of view are represented.

- The settings in which healthcare is currently delivered do not promote health and often make it difficult for providers to deliver high-quality care. Policies, including reimbursement policies, should be developed to facilitate the creation of environments in which providers can remain calm and mindful. This would likely decrease the occurrence of implicit biases and result in the provision of more personalized care for patients, which may also decrease healthcare-related costs over time due to fewer secondary events.
- In addition to language, culture and health literacy have a significant impact on patient-provider communication. Poor communication can occur if the patient and provider speak the same language but have different cultural backgrounds. Cultural influences are diverse even within racial/ethnic groups. For example, young people may be influenced both by the traditional cultural elements of their families as well as modern cultural factors.
- Age, race, and family history are risk factors for prostate cancer, but little is known about the factors that correlate with prognosis. It is hoped that research on combinations of potential risk factors (e.g., gene-neighborhood interactions) will be informative. It is likely that environmental factors play a role in prostate cancer, but it has been difficult to identify them. This may be in part because prostate cancer is a heterogeneous disease; identification of prostate cancer subtypes may facilitate identification of environmental contributors to the disease.
- Trained interpreters must attempt to accurately convey the provider's message to the patient. If the patient does not understand what has been said, the interpreter should ask the provider's permission to expand or clarify. Interpreters should not interject their own values or opinions.
- Providers should utilize a personalized approach to patients rather than relying on racial classification, which can lead to inappropriate assumptions. It is also important that consideration be given to how information gained through research can/should be used to inform clinical decision making.
- There is knowledge being generated about language barriers and ways to address them, but this knowledge is not effectively disseminated to those who would benefit from it. A national focus is needed to help compile and disseminate this important information.

PUBLIC COMMENT

Key Points

- Cancer is currently diagnosed and defined based on pathological features, an approach that was established in the 19th century. However, many cancers defined this way will never progress or metastasize. Modern approaches are needed to more accurately identify lesions that will become invasive and warrant aggressive treatment.
- The NCI Cancer Disparity Research Partnership program provides funding for community-based hospitals that treat minority and underserved populations to facilitate access of these populations to NCI-funded clinical trials. The program supports clinical trials accrual, but it has become clear that increased efforts are also needed to improve screening for and detection of cancer among minority/underserved populations. The more recently launched NCI Community Cancer Centers Program should also help improve access of minority/underserved populations to trials.
- Multidisciplinary teams are needed to integrate information about different types of risk factors and exposures in order to elucidate the complexities of disease. It is important that NCI support these types of efforts.

CLOSING REMARKS—DR. LEFFALL

- Dr. Leffall thanked the panelists for their informative presentations.

CERTIFICATION OF MEETING SUMMARY

I certify that this summary of the President's Cancer Panel meeting, *America's Demographic and Cultural Transformation: Implications for the Cancer Enterprise*, held December 9, 2009, is accurate and complete.

Certified by:

Date: March 11, 2010

LaSalle D. Leffall, Jr., M.D.
Chair
President's Cancer Panel