

**PRESIDENT'S CANCER PANEL
IMPROVING CANCER CARE FOR ALL:
APPLYING RESEARCH RESULTS, ENSURING ACCESS,
ENDING DISPARITIES**

June 15-16, 2000
Omaha, Nebraska

OVERVIEW

The President's Cancer Panel was chartered to monitor and evaluate the development and execution of the National Cancer Program (NCP) and to report to the President on barriers to Program implementation. This meeting was the first in a series of regional meetings to explore issues that affect the ability of communities to provide cancer care—including prevention, education/communication, detection, treatment, diagnosis, rehabilitation, palliative, and end-of-life care—to people in the diverse neighborhoods of the Nation. This meeting brought together representatives from eight Midwestern states to discuss these issues, the barriers faced at local levels, and local- and State-level efforts to address them. The State delegations, composed of up to five individuals, also included cancer survivors who described their personal experiences both with the disease and in obtaining needed information and treatment.

MEETING PARTICIPANTS

President's Cancer Panel:

Harold P. Freeman, M.D., Chairman
Paul Calabresi, M.D.

National Cancer Institute:

Maureen O. Wilson, Ph.D., Assistant Director, NCI, and Executive Secretary, President's Cancer Panel
Otis Brawley, M.D., Director, Office of Special Populations Research, NCI
Cheryl Nelson, Office of the Assistant Director, NCI
Jane Daye, Office of Congressional Legislative Activities, NCI

Speakers:

Charles Bennett, M.D., VA Chicago Healthcare (Illinois)
Judy Bentley, President and CEO, Community Health-in-Partnership Services (Missouri)
Diane Brown, Karmanos Cancer Institute (Michigan)
Thomas R. Buroker, D.O., P.C., Medical Oncology and Hematology Associates (Iowa)
Moon S. Chen, Jr., Ph.D., M.P.H., (Ohio)
Maryann R. Coletti, Government Liaison/Patient Advocate, Alvin J. Siteman Cancer Center (Missouri)
Sitki Copur, M.D., Director of Medical Oncology, St. Francis Medical Center (Nebraska)
Kenneth Cowan, M.D., Director, University of Nebraska Medical Center, Eppley Cancer Center (Nebraska)
Mary Lee Fitzsimmons, Executive Director, Indian-Chicano Health Center (Nebraska)
Cassandra Foens, M.D., Community Representative (Iowa)
Lois J. Hall, M.S., Project Director, Breast and Cervical Cancer Project, Ohio Department of Health (Ohio)
Mary Hendrix, Ph.D., University of Iowa (Iowa)
Sherri G. Homan, M.D., Deputy Division Director, Missouri Department of Health, Division of Chronic Disease and Health Promotion (Missouri)
Robert W. Indian, M.S., Chief, Ohio Department of Health (Ohio)
Carol Isaacs, J.D., Deputy Director, Health Legislation and Policy Development, Michigan Department of Community Health (Michigan)

David Johnson, M.D., M.P.H., Chief Medical Executive, Deputy Director for Public Health Michigan Department of Community Health (Michigan)
Peggy Johnson, Susan G. Komen Foundation (Kansas)
Lewis Jones, Jr., M.D., Physician Consultant, Community Public Health, Michigan Department of Community Health (Michigan)
Sue Kocsis, Community Representative (Nebraska)
Sue Min Lai, Associate Professor of Preventive Medicine, Kansas University Medical Center (Kansas)
Nathan Levitan, M.D., Ireland Comprehensive Cancer Center, University Hospitals of Cleveland (Ohio)
Linda Maricle, Susan G. Komen Foundation (Illinois)
John Okerbloom, M.D., Community Representative (Iowa)
David Ota, M.D., Medical Director, University of Missouri, Ellis Fischel Cancer Center (Missouri)
Kelly Bruce Pendergrass, Oncology & Hematology Associates of Kansas City, Missouri (Missouri)
Claudia Perez-Tamayo, M.D., Central Care Cancer Center (Kansas)
Victoria Rakowski, R.N., E.T., Vice President for Cancer Control, American Cancer Society (Michigan)
Eva Seranil, Office of Minority Health and Human Services (Nebraska)
Jackie Shaver, Witnessing in the Heartland (Kansas)
Deborah Turner, Community Representative (Iowa)
Jim Wade, M.D., American Society of Clinical Oncology (Illinois)
Jill Wagner, Case Manager, Allen County Health Department (Ohio)
Claudia Wojdylak, R.N., United Methodist Mexican-American Foundation (Kansas)

JUNE 15, 2000

OPENING REMARKS—MS. CHERYL NELSON, NATIONAL CANCER INSTITUTE

Ms. Nelson opened the meeting in lieu of Dr. Harold Freeman, Chairman, President's Cancer Panel, whose arrival was delayed by severe weather. She noted that:

- Today's meeting is the first in a series of regional public meetings entitled "Improving Cancer Care for All: Applying Research Results, Ensuring Access, Ending Disparities." The concept for these meetings grew out of the Panel's 1999 efforts to evaluate the National Cancer Program (NCP).
- Until recently, most cancer research in the United States was funded by the Federal Government, primarily by the National Cancer Institute (NCI). However, in 1999, Federal support accounted for only 60 percent of cancer research; the NCI share was less than 50 percent.
- We now know that cancer comprises more than 100 distinct diseases. Cancer care options and related technologies have become more diverse. The NCI Cancer Centers Program has expanded, as has cancer communications. Emphasis on tobacco's major role in cancer also has increased.
- There remains, however, a critical disconnect between discovery (the research enterprise) and delivery (the provision of cancer care). Continuing concerns include cancer care and cancer outcome disparities among populations, insufficient emphasis on patient outcomes, lack of consensus as to what constitutes quality cancer care, risk-promoting lifestyles, and a variety of public and private sectors and groups that do not acknowledge their roles in the cancer problem.
- The Panel has concluded that the cancer problem is not just a scientific and medical issue, but a moral and ethical issue. In the war on cancer, access and delivery issues are not being addressed adequately. We have not addressed the cancer problem with an approach that

acknowledges all of the relevant issues and players. We must mobilize the public and the political will to launch and sustain a full national effort against cancer.

- The NCP has evolved into a highly successful research program that should continue to be supported fully.
- Cancer is more than a research problem, yet we continue to address delivery problems with research solutions. Research agencies, including the NCI, are being asked to answer for the consequences of insufficient application; they cannot solve this problem alone. Legislators and policymakers have a responsibility to use their power to address the cancer problem. Payers must accept sound research evidence and provide coverage for preventive, therapeutic, supportive, rehabilitative, and end-of-life care that has been shown to be of benefit.
- The national effort against cancer consists of two interrelated, but separate, components: research and delivery. Translational and applied research should be expanded to speed the development of basic science discoveries into interventions. Delivery includes primary and secondary prevention, cancer control, education, and access to high-quality, evidence-based care. Stakeholders in each component will need to collaborate to ensure that we apply what we know and deliver quality cancer prevention and care to all people. There is a continuing tension between population-oriented and individual-centered approaches to cancer care. Mustering the national will to combat cancer requires comprehensive public education.

The Panel has put forth the following recommendations:

- Barriers that prevent the benefits of research from reaching all populations must be identified and removed.
- It is the responsibility of legislators and policymakers to enact laws and policies to ensure access to quality cancer care for all.
- Mechanisms are needed to ensure that public and private health care payers have access to and understand evidence for health care interventions and incorporate them appropriately into standards of care for cancer.
- Awareness of the cancer problem, as well as current knowledge about prevention and all aspects of care must be increased through culturally appropriate public and professional education.
- Public pressure must be brought to bear in recruiting to the national cancer effort sectors that traditionally have not perceived themselves as having a role in the cancer problem.
- The current and future cancer workforce requires greater training in state-of-the-art cancer prevention and care, and this workforce must better reflect the diversity of our population and be more sensitive to cultural issues.
- The equal importance of the research and delivery components, and the current disconnect between them, must be recognized. Overcoming this divide requires concerted action by all stakeholders. If we do not better connect the research and delivery enterprises, our progress against cancer will continue to be slow, uneven, and incremental.

The Panel has asked the participants at this meeting to join in identifying what is required to ensure that the public receives the benefit of research conducted through the NCP. Toward that end, the Panel has posed the following questions to all speakers:

- What is the disconnect between research and the delivery of proven cancer interventions in your State? Why does this deficiency exist?

- Who is underserved for cancer prevention and cancer care in your State? What are the vulnerable populations?
- What is stopping people with treatable cancers from receiving the most appropriate treatments? Why are people dying of treatable cancers?
- In addressing local and regional cancer issues, how have the economic, political, and public will been marshaled successfully? What problems could not be overcome?
- What do States and communities need to do to provide proven interventions for cancer prevention, cancer control, and cancer care at the neighborhood level to people with cancer and those at risk for the disease?
- What can or should be done at the national level to support local/regional efforts?
- What policy, legislative, and infrastructure changes are needed at the State, local, and national levels?

In addition to the series of regional meetings, additional hearings will be held to explore international health system experiences and discuss the Panel's findings with Federal, State, and other stakeholders. The process will culminate with a report to the President of the United States in late 2001.

**WELCOME—DR. KENNETH COWAN, DIRECTOR
EPPLEY CANCER CENTER AND EPPLEY INSTITUTE FOR CANCER RESEARCH
UNIVERSITY OF NEBRASKA MEDICAL CENTER**

Dr. Cowan welcomed the participants and the Panel, noting that:

- The purpose of the meeting is to help find solutions to the problems preventing many cancer patients in America from receiving the best possible care for their particular disease. This care includes clinical trials of cutting-edge therapies and innovative approaches to preventing and treating cancer.
- There have been many advances in cancer treatment, diagnosis, and management. The success in treating childhood leukemia is an excellent example of the value of clinical research. For decades, well over half of pediatric cancer patients in this country have been enrolled in clinical trials, and the results of these trials have been striking. In the 1970s, only one in ten children with leukemia survived for one year after diagnosis. Today, over 80 percent of children with leukemia survive.
- Results of clinical trials in breast cancer also highlight the value of clinical trials, such as studies of the efficacy of screening mammography, the use of breast conserving surgery, the benefits of adjuvant chemotherapy and hormonal therapy for patients with breast cancer, and the value of Tamoxifen chemoprevention in reducing breast cancer risk in women at high risk for the disease.
- NCI recently released data indicating that from 1990 to 1997, cancer incidence and mortality rates for all cancers combined and death rates for the ten most prevalent cancer sites have all declined. These results also underscore the remarkable advances that have been made in cancer screening, diagnosis, treatment, and prevention.
- The major challenge today is to identify and eliminate the many factors that limit cancer patient access to the best possible treatment. Health care insurance issues, medical coverage, Medicare coverage, cultural issues, and physical access to care are just a few of these factors.

STATE OF NEBRASKA

Presenters:

Dr. Kenneth Cowan

Dr. Sitki Copur

Ms. Sue Kocsis

Dr. Mary Lee Fitzsimmons

Ms. Eva Seranil

DR. KENNETH COWAN

Key Points

- Nebraska has a population of 1.6 million. The State is more than 500 miles long and 200 miles wide; it is the 15th largest State in the Nation.
- Nebraskans face many of the same problems that exist in other Midwestern States, including insufficient access to quality health care by the indigent, the elderly, and new immigrant populations; and cultural issues regarding access to clinical trials. The cultural issues may differ in African-American, Hispanic, Native American, and various immigrant populations. For some rural populations in the State, access to state-of-the-art cancer care is an issue, as is access to health care of any kind.

DR. SITKI COPUR

Background

Dr. Copur is director of the Cancer Center in Grand Island, Nebraska, the third-largest city in the State. Located approximately two hours west of Omaha, its population numbers approximately 40,000.

The American Cancer Society (ACS) estimates that in 2000, 7,300 new cancer cases will be diagnosed in Nebraska (i.e., 148 people per week). Each week, 63 people in Nebraska will die from cancer.

Key Points

- In every case, a cancer diagnosis profoundly affects a family, a circle of friends, co-workers, neighborhoods, and communities.
- The disconnect between cancer research and cancer care delivery exists in three main etiologies. One of these is patient-related factors (e.g., gender, race, socioeconomics, geography, culture). According to the 1998 census, the Nebraska population is 90 percent Caucasian, nearly five percent Hispanic, almost four percent African-American, and a small percentage Asian and American Indian. Median income in Nebraska is \$35,000, which ranks 37th in the Nation for income. A growing percentage of the population is aged 65 years and older, reflecting a growing Medicare-eligible population. Between 1995 and 2025, the number of those 65 and older will increase 43.5 percent, compared with the U.S. expected increase of 45.9 percent. Ethnic and minority populations also are expected to grow.
- The second area includes physician and health care provider-related factors, including training, availability of resources and equipment, and willingness to provide care. Currently, more than 13 percent of the Nebraska population lives in health professional shortage areas; 52 of 93 Nebraska counties are federally designated health professional shortage areas. In addition, more than 72 of the 93 counties are federally designated medically underserved

areas; this situation affects the population's access to health care services. Yet screening rates (e.g., proctoscopic examination among people over age 40, Pap smear among women over age 18, mammography in women over age 40, and clinical breast examination of women over age 40) of these populations who have ever had these tests are similar among Nebraskans, compared with U.S. rates for these screenings. Rates for minority groups, however, tend to be much lower.

- The third etiology—the most important and most correctable—involves third-party payer-related factors—specifically, absent or insufficient coverage for cancer prevention and care costs. Although insurance status in Nebraska (including uninsured rates and public and private/employer sponsored insurance) compares favorably with national averages, virtually all payers deny coverage for clinical trials participation. This is especially important since the best oncology care is found in the clinical trial setting, where patients gain access to the latest treatment advances. In addition, trials minimize the variations in care due to geography and institutional setting. External peer review and auditing provide quality control, and trials generate statistically valid outcome data that advance treatment standards. However, fewer than five percent of adult cancer patients are enrolled in clinical trials. St. Francis Hospital is affiliated with the University of Nebraska Medical Center and is able to offer both its own and the University's lymphoma protocols (and Cancer and Leukemia Group B [CALGB] protocols) to patients. Others, who are able to travel and have the means to do so, are referred to protocols at NCI, the Mayo Clinic, and the M.D. Anderson Cancer Center. In some cases, it has been possible to arrange for patients to participate in protocols at these institutions while remaining in Nebraska. St. Francis also counsels patients on treatment options and provides them data from the NCI's Physician Data Query (PDQ) database.
- Reimbursement policies of managed care organizations and Medicare are major barriers to clinical trial participation. A recent paper in the *New England Journal of Medicine* (Hutchins, et al.) found that patients 65 years and older are significantly underrepresented in clinical trials. The experience of Dr. Copur and his colleagues indicates that this finding (though not specifically explored in the study) is likely due to Medicare denial of coverage for patient costs on clinical trials. More than 50 percent of cancers occur in those over age 65, and 60 percent of patients who die from cancer are Medicare beneficiaries.
- Many of Dr. Copur's patients have written to State and local legislators about coverage for clinical trial participation. Though many positive return letters have been received, to date the situation has not changed markedly.
- Two studies (by the American Association of Cancer Institutes and the Memorial Sloan-Kettering Cancer Center) have shown that care provided on clinical trials is not more expensive than non-trial patient costs. In fact, the studies showed that costs were lower than for standard care, although the difference did not reach statistical significance.
- An increasingly enlightened patient population is demanding access to clinical trials and other benefits traditionally associated with academic centers or research institutions.
- According to Medicare legislation, off-label drug use can be approved if the drug is listed in one of the three major compendia. It also is possible to obtain coverage if a drug is not listed but if peer-reviewed, published literature exists indicating benefit of the off-label use. However, a Health Care Financing Administration (HCFA) Memorandum gives broad authority to its local contractors to evaluate the adequacy of the literature. In many cases, protracted correspondence with the carrier is required to obtain approval, and application of the relevant regulations varies considerably by geographic region and HCFA contractor.

- Dr. Copur noted that the very recent announcement mandating clinical trials coverage for Medicare beneficiaries should greatly improve cancer care for this population, but off-label drug use still remains a major obstacle.

Recommendations

- Coverage for care provided under clinical trials should routinely be made available for all patients.
- People across the Nation should be offered national Cooperative Group trials and other trials listed in the PDQ, using a centralized organization and data collection system available to local oncologists and academic centers.
- Off-label drug use must be revised and centralized. Only highly competent experts—either at the nurse or the non-oncologist level—should make decisions about off-label drug use, not the local carrier. More flexibility and uniformity of use should be allowed across the United States.

MS. SUE KOCSIS

Background

Ms. Kocsis was diagnosed with breast cancer at age 34. While a health maintenance organization (HMO) enrollee, she saw four different physicians who failed to diagnose her disease. Repeated mammograms failed to show an abnormality. She was told the lump she felt was fibrocystic breast disease and that she was too young to have breast cancer. Ms. Kocsis changed health plans to a preferred provider organization (PPO), which enabled her to return to the obstetrician who had delivered her children. This physician performed an excisional biopsy that revealed a two-centimeter tumor with no lymph node involvement. The time elapsed from when Ms. Kocsis first presented to the HMO with symptoms until her diagnosis was nearly 20 months. At the time of her diagnosis, she had three children, aged two, five, and eight years. She felt angry and hurt that her HMO had apparently chosen to control costs at the expense of her health.

Ms. Kocsis underwent chemotherapy, which caused premature menopause. She also underwent a hysterectomy. Although she did not fear death, she feared dying an angry person and the prospect of her children losing an essential part of their childhood to the experience of countless hours spent in hospitals due to her illness. Eventually, Ms. Kocsis decided that her anger was unproductive for her, and instead became involved in legislative issues related to cancer. Later, she also had reconstructive surgery and reached the milestone of five-year survival of her disease.

However, seven years after her diagnosis, a solid tumor was found in her lung and she underwent a thoracotomy. Once the tumor was determined to be recurrent breast cancer, she underwent high-dose chemotherapy at Johns Hopkins Medical Center after traveling to consultations at the M.D. Anderson Cancer Center, Memorial Sloan-Kettering Cancer Center, and the Mayo Clinic. Though the treatment was difficult, and she experienced treatment delay due to Cytoxan-induced hemorrhagic cystitis, she completed the treatment. Shortly afterward, however, liver metastases were discovered, and Ms. Kocsis had to return to treatment. Currently, she is undergoing further chemotherapy, but has become jaundiced and frequently has to have fluid drained from her abdomen.

Ms. Kocsis indicated that she thinks every day about living with cancer, but thinks far less frequently about dying from her disease. She is grateful to have survived for the last eight years to see her children into their teenage years.

Key Points

- The value of feeling lucky as a cancer patient is priceless. Earlier detection of disease and physicians who are truly the patient's advocate—regardless of insurance coverage—and dedicated to finding the cause of symptoms rather than just treating them, would be of priceless value in our country.
- Efforts to pass Patient Bill of Rights legislation and patient self-advocacy have been important advances in the past eight years.

DR. MARY LEE FITZSIMMONS

Background

Dr. Fitzsimmons is director of the Indian-Chicano Health Center in Omaha, a community health center serving about 20,000 uninsured and underinsured patients, including many Hispanics, Native Americans, and Sudanese, a rapidly growing population of new immigrants. Eighty-seven percent of families served by the center have incomes at or below 185 percent of the Federal poverty level; most are at 133 percent of the poverty level. For a family of four, this equals approximately \$1,900 per month. The average wage is \$8.79 per hour, or just over \$18,000/year. Average family size is 5.2. Of the families seen at the Center, 87 percent are not functionally literate in English.

The Center does not receive Federal Bureau of Primary Health Care funding, but depends primarily on the generosity of the medical and health community in Omaha and United Way support.

Key Points

- The Center defines cancer care broadly to include cancer prevention, education, screening, and treatment. The obvious barriers to providing care are poverty, lack of health insurance, cultural norms, limited knowledge of English, lack of reliable transportation, and mistrust and lack of understanding of the American health care system.
- The health care system itself is frequently a barrier because it is vastly different from those to which many immigrants were accustomed in their countries of origin. Relational medicine is most successful with many of the new immigrant groups, but it is not possible with the rotating staffs of many of the community-based clinics and in most major medical institutions. In these settings, continuity of care and the establishment of strong relationships between the patient and family and the treatment team are unlikely; thus, the system itself becomes the barrier.
- In addition, the general literacy level in the family's language of origin is a critical barrier because public school infrastructures in many patients' countries of origin have frequently been disrupted by civil strife. Many patients and families served by the Center cannot read at a fifth-grade level in their native language. NCI and American Cancer Society (ACS) pamphlets are written at a tenth-grade level or above, and the reading level is equally high when the materials are translated into different languages. The Center looks for pictures and photos that will help in communicating with patients with limited literacy. Informed consent materials for clinical trials require an even higher reading level and pose a serious challenge to obtaining truly informed consent from patients.
- Additional barriers are related to the acculturation level of immigrant families. In many cultures, for example, women must receive permission from an authority source before they can receive screening or treatment. This value, foreign to American traditional medical

culture, cuts across many racial and ethnic groups and changes with increasing acculturation. Assessment of family and patient attitudes is essential to effective cancer education, prevention, early detection, and treatment.

- A common expectation among health care providers is that a family will be able and will want to obtain information from written material. This expectation is uniquely an American and Western European cultural value. In other cultures, people seek information from someone they trust, yet such persons may not always be well informed about cancer prevention or treatment. It is not surprising that providers hand out a pamphlet and then complain that education did not lead to behavior change.
- A system-related barrier occurs when there is a lack of local public health capacity and leadership to create community norms on the issues of cancer education and cancer prevention. This issue is particularly relevant to new immigrants and the poor. For example, tobacco use among youth is a general public health issue, not specifically a health center or school system issue. Tobacco use is determined largely by community norms across many levels. Therefore, public health leadership and public health capacity at the local community level must address it, and public health funds are needed to support this activity. The source of such funding (e.g., Federal, State) is unimportant; it is critical, however, that the interventions are community-based. Similarly, interventions to control sexually transmitted infections must also be community-based; the relationship between human papillomavirus (HPV), hepatitis B, human immunodeficiency virus (HIV), and cancer is well documented. In these examples, cancer care and cancer control become public health functions and must be supported as such. There remains a dearth of local public health focus in these areas.

MS. EVA SERANIL

Background

According to the ACS, an estimated 7,400 new cases of cancer were expected in Nebraska in 1999, including 1,000 new lung cancer cases, 1,000 new colorectal cancer cases, 1,100 new prostate cancer cases, and 1,000 new breast cancer cases. It also was estimated that 3,400 cancer deaths would occur in Nebraska in 1999. Many of these deaths could be prevented through increased cancer prevention and screening and improved access to medical care.

The public health effort in Nebraska continues to strengthen existing infrastructures to improve service to all populations. Its focus is on assessment, policy development, accurate and up-to-date data, and population interventions. The Office of Minority Health monitors disparities in cancer care among ethnic, minority, and underserved populations.

Ms. Seranil is Administrator of the Nebraska Office of Minority Health and Human Services. Previously, she was an outreach worker for a nationwide breast and cervical cancer early detection program, a position that provided a unique opportunity to observe the real problems experienced by real people in the community as they attempted to obtain optimal care.

Key Points

- Many in Nebraska face challenges in receiving cancer prevention, screening, and other services, particularly the uninsured, underinsured, and racial and ethnic minorities (10.3 percent of the population) in both urban and rural settings. For example, African-American women in Nebraska are three times more likely to die from cervical cancer than are white women. In addition, a physician visiting the Santee Indian reservation reported an unusually

high rate of prostate cancer cases in that population, although data do not exist to substantiate this observation.

- Advocates, community representatives, and professionals believe that culturally and linguistically appropriate education is lacking for medically underserved, underinsured, uninsured, and racial and ethnic populations. This education is needed to explain basic facts about cancer, how and where to go for services, and why it is necessary to get different components of cancer care at different locations. A linguistically matched guide is needed to help people navigate the system. Underutilization of cancer care is also affected by patient feelings that they will not be treated fairly or humanely.
- Additional barriers include inability to pay, lack of insurance among service and farm workers, underinsurance for cancer care, culturally grounded beliefs (e.g., taboos, traditions, spiritual perspectives), and childcare and transportation problems, particularly for rural populations. People also avoid screening and treatment because of fear of the unknown, fear of the system, fear of pain, and concern about loss of employment that could result from time missed from work to obtain treatment. Some also fear the loss of a significant other, who might abandon a partner diagnosed with cancer.
- Mistrust and language differences may be the most difficult barriers, since people need to bond with the provider—difficult in the fragmented health care system—and it is believed that 26 languages are spoken by the diverse populations in Nebraska, posing a significant challenge to outreach workers and providers attempting to communicate cancer information in written or oral form.

Recommendations

- To address local cancer issues, various constituents of the economic base, political arena, and public need to unite as a team to ensure that all populations have meaningful access to care. This includes providing job security with a reasonable health plan, a national act to provide cancer prevention and treatment programs, and the formation of local coalitions. State partnerships have proven effective in providing interventions across the cancer continuum to people at the neighborhood level.
- Funding is needed to provide screening and care of all types; fragmented funding that supports only certain services is not adequate to stop the staggering number of cancer deaths in Nebraska and the Nation.

DISCUSSION—STATE OF NEBRASKA

Key Points

- Younger women who present with breast symptoms are frequently told they are too young to have breast cancer and may be denied diagnostic mammograms and treated instead for fibrocystic breast disease (via vitamin E and elimination of caffeine from the diet). Many are finally diagnosed, but with advanced disease. Women's intuition about their bodies should not be dismissed. Primary care physicians need to be educated that younger age does not necessarily mean lack of disease. Medical training for primary care providers and obstetrician/gynecologists does not adequately cover breast care.
- Attempts to constrain screening costs also contribute to failure to screen younger individuals for cancer. There is a tension between individual- and population-oriented approaches to screening. In addition, physicians may face criticism from peers and payers if they are perceived to be performing too many screens and biopsies on people who fall outside of

standard screening parameters. However, younger patients who present with symptoms, particularly those with a family history of cancer, must be taken seriously. Younger female patients are also more likely than males to experience condescension from physicians when they request diagnostic testing for cancer. It also was noted that concurrent medical conditions experienced by a patient of any age may keep a physician from appreciating and acting on possible signs of cancer.

- Though much is said about access issues among rural populations, the uninsured, minorities, and others, it also should be noted that insured white males often do not access services because they perceive themselves to be too busy or too invincible to need care. Some do not want to know if they have a health problem because they fear treatment or the impact illness would have on their lives. These dynamics also are part of the problem in getting the best available care to all parts of the population.
- Some of the drugs approved for cancer care by Medicare are outdated for the treatment of specific cancers. If patients are to get the best available care, Medicare's drug list must be kept updated. Oncologists who follow the literature and try to provide the most up-to-date care for their patients face multiple inquiries from local Medicare contractors when they wish to provide a particular drug regimen. The time spent corresponding with the local Medicare directors, providing copies of the relevant literature, and waiting for approval takes weeks or months. A time lag of this duration can be extremely dangerous for patients, particularly for those who are diagnosed with advanced disease.
- Progress against adult cancers would occur more quickly if more people enrolled in clinical trials, which are the mechanism by which the standard of care is advanced. It is difficult to ensure appropriate informed consent from populations with low literacy and/or whose native language is not English.
- Two schools of thought exist as to the relative value of taking screening services to the population versus bringing people in from underserved areas to the medical "home" (i.e., clinic, hospital, medical center). Those who favor mobile services believe taking the service to the community overcomes many of the barriers (e.g., transportation) that prevent people from obtaining screening or other services. Those who believe the patient should be brought to the medical facility believe there is less likelihood that patients with identified abnormalities will fail to receive needed treatment. In addition, taking services (e.g., prostate screening) to the work site may be unacceptable to some populations.
- In the new immigrant populations and in the South Omaha area, patients who are due for screening are picked up in a van if they have transportation problems. The van is supported by United Way funding. This approach has been taken because bus service in Omaha is inadequate. Providing this service is part of the relational medicine that is key to effective interaction with underserved patients. More than just providing a ride, the service shows the patient that his or her need is recognized and that efforts are being made to meet that need.
- Transportation is as much a barrier to early detection services as to treatment services. However, it is easier to get volunteers to take people to their cancer treatments than to screening; helping people obtain treatment is somehow more emotionally satisfying to the volunteer than driving a person for a Pap smear, for example. Yet, the issues—barriers associated with culture and poverty—are the same.

STATE OF INDIANA

Presenters:

**Ms. Joni Albright
Dr. William Dugan
Mr. Greg Poe**

MS. JONI ALBRIGHT

Background

Indiana's population numbers 5.8 million. The 2000 census is expected to show that the population is approximately 15 percent minority, including African Americans and a rapidly growing Hispanic population. In addition, Indiana has a sizable Amish population, to whom it is quite difficult to provide health services. About half of the population is in six urban areas that have traditional urban problems; the other half of the population is dispersed throughout rural Indiana. Two-thirds of Indiana's counties are federally designated underserved areas.

The Indiana Department of Health receives approximately \$200 million per year in State and Federal funding (from 40 to 50 sources) to fund all public health services. The job of the Public Health Service Commission is to collect these monies and then rapidly deploy them to communities to support local programs.

Indiana has identified cancer health disparities among its populations, and has pieced together a cancer control program that includes an award-winning geographic information system (GIS), tobacco abstinence programs for teens, and other programs. Access to primary care and fragmentation of care are major issues.

Key Points

- Currently, State Health Department program managers who manage multiple grants from the Centers for Disease Control and Prevention (CDC) must contend with multiple program directors, site visits, conferences, data reporting requirements, and reporting software. This problem is multiplied at the local level and is particularly onerous in smaller towns, where reporting and other requirements continually fall on the same providers.
- Money tends to be allocated by body part—if monies could be blended, the State could better fashion a comprehensive cancer control program that could be administered more efficiently and flexibly by the smaller governmental staff demanded by voters.
- Planning at the State level is made difficult by the need to apply for multiple grants to support a single project or program. If one or more of the grants is not funded, it is difficult to sustain the program or launch new efforts.
- Indiana's legislature had allocated every dollar of its tobacco settlement money to health care and public health. These funds will go to community health centers, tobacco control programs, prescription cost coverage for seniors, and, importantly, to local health departments, whose current infrastructure is weak. The State also plans to use some of the money to improve the cancer registry.
- Members of the legislature understand the value of good data to program planning in public health. A legislative study commission is evaluating childhood environmental issues in cancer control. There also are plans to establish a statewide cancer advisory board.

Recommendations

- The possibility of combining cancer control funding from multiple sources, particularly different components of the CDC, into a State block grant should be considered to streamline funding of community-based programs. A chronic disease block grant would have even more beneficial effects.

DR. WILLIAM DUGAN

Background

Community Cancer Care (CCC) is an Indiana health care corporation serving primarily the underserved and rural areas of the State. Its service area covers approximately two-thirds of the State. It is a data-driven, outcome-oriented project that strives to build on existing infrastructure and avoid duplication of effort. Privately owned, CCC has been in operation for 17 years on a fee-for-service basis.

Cancer survival statistics for the areas served by the CCC are as good as those of the largest medical centers in the State and the Nation, but CCC serves a greater percentage of patients aged 70 and older. CCC emphasizes continuing medical education for local doctors, nurses, staff, and patients.

CCC has a not-for-profit component through which research is conducted. A key project is the Oncology Symptom Control Research group that develops, implements, and validates evidence-based treatment road maps for all of the common symptoms experienced by cancer patients. Its work has been widely published.

Key Points

- Cancer control is really technology transfer; research is useless if it does not reach the people.
- It has been said that the first decision in cancer management determines the success of the outcome. In rural and underserved Indiana, these first decisions are being made by the physicians with the least cancer management experience. In some cases, older people are not getting up-to-date care, or even *any* care. Part of the problem has been a lack of infrastructure, particularly in the number of primary care doctors. In Indiana, 75 percent of physicians are specialists; only 25 percent are primary care providers. This situation also exists in other parts of the country. Most of the specialists are concentrated in the urban areas and see only patients who are funneled to them through the system.
- Rural capacity for chemotherapy administration, and reimbursement for these services, is poor. Most of the specialists who travel to rural areas tend to take patients back to the urban areas for treatment because reimbursements are higher in the metropolitan areas.
- Funding for cancer control research is limited—in part, because the science is not as well defined as in other research areas. Few academic chairs exist in cancer control research.
- Research in the community will wither unless ways are found to accomplish clinical research with the same ease with which routine patient care is carried out. Moreover, patient care must be accomplished with the same thoroughness as clinical research. Accomplishing both requires sophisticated information technology systems—medicine currently is less computerized than Wal-Mart.
- CCC is implementing a Canadian paperless OPTX system. Perhaps the most important feature of the system is that all procedures are described in the system and immediately accessible.

- Community clinical research is usually funded through institutional subsidies; this is an unpopular option because it is unclear who is paying for the research or where the money is coming from. In addition, subsidies are becoming more uncertain as profit pressure increases on the cancer care infrastructure. Reliance on grant funding thwarts efforts to hire the best staff or physicians, who may doubt the stability of employment with the institution. Endowment is the preferred method of funding clinical research since it provides greater stability to the research infrastructure. However, it requires more sophistication and organization than exists in most private practice settings.
- Making community clinical research financially feasible takes strict budget control. CCC data show that in 1996, costs per patient enrolled on a clinical trial totaled \$3,600. Since cooperative group trials pay only about one-third this amount, for every patient on a cooperative group trial, it is necessary to place a patient on a pharmaceutical industry-sponsored trial that pays \$6,000 to \$8,000 per patient.
- Health care providers must have data on all aspects of care. A recent CCC survey of 1,100 ambulatory patients, published in the *Journal of Clinical Oncology*, showed that doctors and nurses missed severe depressive symptoms in patients 75 percent of the time. Some patients do not get blood chemistry analyses that would identify the cause of many of their symptoms. It also is true, however, that some disagreement exists as to what chemical profiles should be performed, and reimbursements may not be aligned with the most effective care.
- Precertification is not cost-saving, is frustrating to all concerned, and is largely unethical. Physician and hospital motivation should be accomplished by providing feedback and conducting audits of outliers.
- Without proper integration of primary care into the cancer care system, specialty medicine will continue to provide costly solutions to simple and inexpensive problems. No amount of good intention, planning, or regulation will improve cancer care unless discoveries are provided to the people in the trenches.

Recommendations

- Financial incentives are needed to encourage and enable oncologists to provide chemotherapy services in rural settings instead of transporting patients to the cities.
- A single chemistry profile should be established for every important medical interaction; duplication must be avoided.
- Drug costs and reimbursements are an issue for all citizens. Current reimbursement schedules for chemotherapy are based only on drug cost and do not provide for administration-related costs. This situation should be remedied.
- Information systems should be integrated to include primary care physicians, consultants, laboratories, pharmacies, hospitals, nursing homes, and billing and collection systems. The current lack of system integration is wasteful and duplicative.
- Reimbursement for chemotherapy should not be tied to labeled or off-label use. Instead, it should be governed by objective measures and tolerable toxicity.

MR. GREG POE

Key Points

- Many primary care physicians face significant time constraints that limit their consumption of information about recent research results relevant to their practice. Many routinely work 12- to 15-hour days, including hospital rounds, office hours, and administrative tasks.
- Primary care physicians also face resource constraints; urban and rural providers have limited access to anything more than basic care resources. Decreasing reimbursements limit capital and procedural expansion. In addition, both urban and rural physicians experience geographic isolation and isolation from interaction with peers. Professional isolation means that physicians lack a forum for exchanging ideas and information about clinical advances.
- Consumers of safety-net services (e.g., community health center patients) tend to present with acute maladies rather than seeking care for chronic ailments or preventive services.
- Research results should be transmitted to providers in usable ways. Continuing medical education conferences are usually held in the urban areas, creating a barrier for rural physicians.
- Rural primary care physicians are geographically isolated from specialists and subspecialists, making referrals difficult.
- Patient adherence to recommended treatment is another barrier to effective care. Some patients lack an ongoing relationship with a primary provider, resulting in poor continuity of care and inappropriate emergency room use.

Recommendations

- Provide data on research results to primary care providers in understandable and usable formats.
- Emphasize to primary providers the importance of professional interaction and clinical interfaces to the application of the best possible care. Promote collaboration and communication between isolated primary providers and specialists and subspecialists throughout the region or State.
- Make clinical protocol development and outcome measurement a provider priority. Find incentives for primary care providers to emphasize disease prevention and chronic disease management.
- To the extent possible, regionalize continuing medical education and training for isolated providers by promoting interactive distance learning.
- Emphasize the patient's responsibility in his or her health in the areas of prevention, chronic disease management, and adherence to treatment plans.

DISCUSSION--STATE OF INDIANA

Key Points

- CCC's group of 21 medical oncologists is about to join the largest radiation therapy group in Indiana; this action reflects a belief that these two oncology specialties need to collaborate on the most effective approaches to many cancer problems. Further, this collaboration should be useful in that it presents a united front to government, the insurance industry, and the public. It also is most beneficial to patients.
- Oncology practice is a local effort that does not lend itself to centralization. Networks such as CCC are important to the practice of community oncology. The importance of providing support for chemotherapy administration costs (as opposed to reliance on drug costs as the primary source of income for private practice oncologists) was underscored. Unless this problem is alleviated, clinical research in the community will not be able to take place. HCFA regulations have been a major barrier in this area, and with new regulations taking effect October 1, 2000, that will pay only drug acquisition costs, the situation will worsen.

Recommendations

- Although consolidated or block grants from the CDC would streamline funding at both the State and local levels, the CDC needs congressional authorization for comprehensive cancer control funding. At this time, the only CDC funds specifically authorized for cancer are for the Breast and Cervical Cancer Screening Programs, the registries, and some tobacco use prevention efforts. Moreover, even these funds are inadequate to provide services to the populations that need them. Because funds cannot be commingled, administrative costs for the State and local programs are unnecessarily high.

STATE OF MICHIGAN

Presenters:

Dr. David Johnson
Ms. Victoria Rakowski
Dr. Lewis Jones
Dr. Diane Brown

DR. DAVID JOHNSON

Key Points

- Data for 1998 show that overall cancer mortality rates in Michigan are 30 percent higher for African Americans than for whites. Overall breast cancer mortality rates are falling in Michigan—as they are nationally—but remain higher for African-American women compared both to white women in Michigan and the national average. A similar disparity exists for cervical cancer.
- Prostate cancer incidence and mortality rate trends in Michigan mirror the national trends, though the rates are slightly higher.
- Michigan lung cancer mortality rates are considerably higher than the national average. Rates are higher for men than for women, but the mortality rate is decreasing for men while rising for women. African Americans in Michigan have higher lung cancer mortality rates than whites.
- Colorectal cancer mortality rates are declining slightly in Michigan; disparity in mortality also exists between black and white populations for this cancer.
- In Michigan, mammography rates have improved significantly over the past 10 years for women aged 40 years and older, yet 47 percent of women do not received appropriately timed breast screening (mammography plus clinical breast examination). Women are less likely to receive screening at recommended intervals if they are of lower educational status, lower income status, uninsured, or over age 75.
- Over 95 percent of women in Michigan have had at least one Pap smear, but only 65 percent have had this test in the past year. Women are less likely to receive cervical cancer screening if they have low incomes, less than a high school education, or are over age 64. Pap smear screening rates for African-American women are comparable to those for white women, but their cervical cancer mortality rates are higher.
- Only 43 percent of men and women aged 50 and older have had a fecal occult blood test (FOBT); only 48 percent of men and women 50 or older have had a sigmoidoscopy at least once. Those less likely to receive colorectal cancer screening include those under age 60, African Americans, and surprisingly, those with higher education and income.
- Tobacco use is a major challenge in Michigan. The overall smoking rate for 1997 was 26.2 percent; this rate has remained level over the past decade. Among men, 29.6 percent smoke; 23.1 percent of women smoke, and their rate appears to be increasing. Smoking among whites is slightly more prevalent than among blacks (26.3 percent versus 24.8 percent, respectively). Smoking rates in Michigan are about the tenth highest in the Nation.

- Data for 1996 show that 32 percent of adults in Michigan are overweight, and this percentage is believed to be increasing. Michigan has one of the highest obesity rates in the country.
- Twenty-three percent of Michigan adults engaged in no leisure time physical activity; 77 percent reported they did not engage in regular and sustained activity. Only about one-fifth of Michigan adults report consuming five fruits and vegetables daily.

MS. VICTORIA RAKOWSKI

Key Points

- The current disconnect between research and delivery in Michigan can be attributed at least in part to a combination of patient, provider, and health system barriers. Patient barriers include lack of information and misinformation about cancer risk, benefits and risks associated with treatment options, the nature and purpose of clinical trials and end-of-life care, lack of access to health care in general, and lack of a primary care provider. Particularly in the urban centers, people go for health care to emergency rooms instead of a primary care provider. There is significant confusion about screening guidelines. Other patient barriers include cultural beliefs and language barriers. For example, the Detroit area has a very large, newly arrived Arab population, as well as Vietnamese and other Asian immigrants. Moreover, there is a significant African-American and rural population in the State that is seriously underserved in terms of cancer messaging efforts. Other patient barriers include financial issues (uninsured, underinsured, lack of coverage for care in clinical trials), geographic barriers such as transportation to care, and fear and mistrust of the health care system.
- Provider-related barriers also contribute to the disconnect between research and delivery. These barriers include knowledge deficits concerning appropriate screening; appropriate followup of abnormalities; clinical trials; and palliative care, especially pain management. Other provider barriers include lack of effective strategies for changing physician behavior, time pressures that affect attention to age- and risk-appropriate screening, confusion about screening and followup guidelines, and physician bias (e.g., not appropriately screening the elderly, value of participating in clinical trials, late or no referral to end-of-life care). While the physician community has been very supportive of the Breast and Cervical Cancer Screening Program, there is still much work needed to overcome provider barriers related to other cancers.
- Health system barriers include geographic inaccessibility, physical inaccessibility (a particular issue for the elderly and disabled), lack of culturally sensitive providers, and lack of effective tracking and reminder systems and case management for individuals with abnormal screening results.
- To address these barriers, Michigan is developing a statewide infrastructure for improving cancer care: Comprehensive Cancer Control through the Michigan Cancer Consortium (MCC) Initiative. It is a statewide public-private partnership designed to achieve TOP cancer control priorities in Michigan. The MCC began in 1986 as a group of individuals with an interest in cancer and served as an advisory board to MDCH. The MCC has grown to a network of more than 30 organizations in which each participating organization is committed to doing its part to achieve the stated goals. In addition, expert panels developed ten programmatic and system-oriented priorities for the next four years in the five most prevalent cancers and for primary prevention. Over 100 organizations worked together to develop action plans to address each priority, with significant input from the community and from

underserved populations. Guiding principles were to make data-driven decisions whenever possible, to use resources efficiently, and to collaborate to maximize statewide impact.

- The MCCI Strategic Plan has just been published and has the commitment of the many organizations that participated in its development. Each is contributing its networks, sharing resources, and facilitating new partnerships. In addition, each participating organization agrees to provide an annual report on its efforts to help keep the effort on track and share ideas. The effort as a whole will be guided by a 30-member board; four members of which will represent special populations to help ensure that disparities are addressed.
- The challenge will be to keep the participating organizations enthusiastic and committed to the effort.

DR. LEWIS JONES

Key Points

- In Michigan, early detection of breast cancer has increased over the past decade due to implementation of the Breast and Cervical Cancer Screening Program, public education campaigns, and the work of myriad public and private partners to improve outreach and physician education about the importance of mammography screening. In contrast, rates in early detection of colorectal cancer have changed little in the past decade because the same level of resources have not been directed to this disease.
- To implement its Breast and Cervical Cancer Screening Program, Michigan has partnered with the Federal CDC program and with the State family planning program. Barriers being addressed include program limitations regarding followup of detected abnormalities, financial access, and health care system gaps. Through a pilot effort, both the screening program and the family planning program contribute funds for colposcopy and other diagnostic procedures for women with abnormal Pap smears. In the first nine months of this pilot effort, 140 women were referred for followup care; 8 percent were found to have cancer. This program has benefited predominantly uninsured and poor women. Michigan would like to expand the program statewide and include the sexually transmitted disease program to help reach the segment of women at high risk for cervical cancer.
- Michigan's goal in providing prostate cancer education for African-American men is to provide objective information on prostate health, including screening. Barriers include the controversies related to screening, distrust of the medical establishment, and lack of knowledge or misinformation. To address these problems, the Michigan Department of Health has funded two hospital-based education projects and one church-based project. The projects encourage men to discuss screening with their physicians and provide accurate information to support informed decisionmaking.
- Michigan's tobacco control project targeting communities of color funds ten community-based agencies to support programs on smoking prevention, cessation, and secondhand smoke. Barriers being addressed by operating these programs in the communities include culture and language differences and distrust of the medical establishment. Other barriers to be addressed include addiction and peer pressure. Targeted populations include African Americans, Hispanics, Native Americans, Asian Americans, and Arab Americans.
- The Women's Cancer Screening Recruitment Project seeks to increase the number of the hardest-to-reach women screened through the breast/cervical cancer screening program and to increase the number of African-American women enrolled in the program. The program addresses barriers including limited access to health and medical care, distrust of the medical

system, and lack of information or misinformation. It is the latest in a long series of outreach projects supported by the breast/cervical screening program. Women considered hardest to reach are those who have never been screened, have not had a Pap smear in the previous five years, or have not had a mammogram in the previous two years. The project operates by providing grants to community programs to do outreach or “inreach” to help providers refer eligible women. Potential applicants include tribal groups, local health departments, and medical providers. The program attempts to use trusted community groups to circumvent some of the usual barriers to care.

- Similarly, the Healthy Asian Americans project promotes breast and cervical cancer screening and early detection in this population. Primary barriers to care in this population are cultural and language problems and distrust/fear of the medical system. The project has the extra challenge of needing to develop and distribute information materials in English and five Asian languages. It also provides transportation and interpreter services to those who need them.

DR. DAVID JOHNSON (summary)

Key Points

- Funding for Michigan’s cancer control efforts is a mix of public and private support. Most of these monies support services to the public; a portion is spent on applied research and demonstration projects.
- Executive level support has proven highly valuable in furthering State efforts to improve cancer care services. The State’s First Lady is an active supporter of diverse activities, such as the Komen Race for the Cure, the annual Heroes of Breast Cancer luncheon, and a variety of campaigns to increase use of mammography services. The Governor, his mother, and the First Lady also have participated in mammography campaigns.
- State policy support has likewise been important in establishing and maintaining services related to breast and cervical cancer, the tobacco control program, an internal cancer steering committee and departmental cancer plan, and several other programs.
- Future challenges for Federal-State partnerships in Michigan include further support for expanding insurance coverage for those currently uninsured, including the sexually transmitted disease program in the current partnership between the Family Planning and Breast/Cervical Screening Programs, and improving State focus on early detection and treatment of colorectal cancer.

Recommendations

- Need to increased State flexibility for spending Federal cancer dollars.
- Federal interagency communication and collaboration should be fostered.
- As the pace of discovery increases, so will the need to focus on research dissemination and diffusion.

DR. DIANE BROWN

Background

Among Michigan residents, cancer mortality rates are particularly high in the Detroit metropolitan area, especially in its African-American population.

Key Points

- To help target cancer education, prevention, and control to the at-risk segments of the Detroit area population, the Karmanos Cancer Institute conducted telephone surveys of area residents in 1996 and 1998. The first survey included only African Americans; the second included Caucasians and those of other ethnicities. Among the more interesting findings concerning women respondents were that: women with a stated religious affiliation were more likely to use mammography services than those without such an affiliation; among women who had not had a mammogram in the previous year, the primary stated reason was lack of need or desire (others cited cost, procrastination, and lack of physician recommendation). Male participants in the survey were queried on their understanding of the prostate and prostate cancer. About half did not know some of the signs of prostate cancer; this and other responses varied by age and level of education, with older and better-educated men being better informed. A large majority of the male respondents believed that the prostate specific antigen (PSA) test was a good idea and that a normal PSA could provide peace of mind.
- The survey also elicited information on behavioral and lifestyle risk factors. Approximately 30 percent of respondents indicated current tobacco use; 84 percent of smokers said they would like to quit, but only 54 percent had been advised to do so by a doctor. Two-thirds of respondents were not familiar with the Five-a-Day initiative to increase consumption of fruits and vegetables. The greatest variation noted was by gender, with more women familiar with the program than men. Thirty-eight percent of respondents said they ate five or more servings of fruits and vegetables daily.
- In addition, the survey assessed respondents' cancer-related beliefs and attitudes. Most respondents appeared to be well informed and knowledgeable about cancer and its potential impact on their lives. Slightly less than two-thirds expressed agreement with a statement that belief in God or strong faith can cure cancer; however, African Americans were more likely to agree with this statement than Caucasians. Yet, approximately equal proportions of the respondents agreed with the statement that when a person is ill with cancer or another serious disease, it is due to God's will or fate.
- On most indicators examined in the surveys, there was little change between 1996 and 1998. However, increases were noted both in African-American women's use of mammography and African-American men's knowledge about the location of the prostate gland and facts about prostate cancer. In addition, the comparative analysis suggested that tobacco use is declining.
- Knowledge about clinical trials appears to be moderate to low among both African-American and Caucasian populations, but is higher among Caucasians. Awareness of the Federal regulations for the protection of human subjects is low, and African-American respondents expressed less belief that scientists follow these regulations, probably reflecting distrust of the medical establishment in that population. Efforts are needed to increase awareness of clinical trials and human subject protections.

- While mammography screening utilization is relatively high in the Detroit area, it is still underused by low-income women, and issues remain concerning adherence to guidelines. Continued outreach and education are still needed to encourage regular breast self-examination among all women and to increase prostate knowledge among men. In addition, efforts are needed to encourage greater consumption of fruits and vegetables.

DISCUSSION—STATE OF MICHIGAN

Key Points

- Dr. Brown indicated that the data provided came from the State's cancer registry, which has been operational for more than 20 years.
- Clinical trials have not been a priority at the State level in Michigan until recently. Responsibility for encouraging participation had been left to the investigators conducting the trials, but now a much broader cross-section of the public and private sector have taken responsibility for educating the public about the importance of trials and how they can provide direct benefits to the individual and influence the outcome of cancer. Lack of reimbursement for patient care costs on trials has been another reason trials have not received strong support. The State has recently assembled a large panel of individual organizations and collaborative efforts to address this issue. Several legislators, including one who is a physician, are spearheading this effort. It will be based on the voluntary model adopted in New Jersey, rather than mandated coverage.
- Many of the women with abnormalities detected through the screening programs described are subsequently treated at university medical centers, though data on the percentage of all women requiring followup treatment were not available. In addition, Michigan hospital cancer programs are well distributed geographically, enabling women to obtain treatment in their communities. Complex procedures, such as bone marrow transplants, are only done in Detroit, Ann Arbor, and, to a lesser extent, in Grand Rapids.
- In developing its collaborative cancer control plan, no organization approached refused to participate. Response from industry has been strong. There has been little or no problem with infighting or territorialism. It will remain to be seen whether this level of enthusiasm and involvement can be maintained.
- It is important that all of the factors contributing to cancer trends (either within a State or compared to regional or national statistics) are identified and their relative importance attributed.

STATE OF MISSOURI

Presenters:

Ms. Sherri Homan
Ms. Maryann Coletti
Dr. Kelly Pendergrass
Dr. David Ota
Ms. Judy Bentley

MS. SHERRI HOMAN

Background

Missouri's public health system includes Department support units, three centers, and six programmatic divisions, one of which is the Division of Chronic Disease Prevention and Health Promotion. The State also has 114 autonomous local public health agencies that are funded in part by tax incentives and other monies and, minimally, by State funds. The State Health Department works closely with these local agencies.

Missouri believes the public health system has a large role to play in providing complete and accurate data and timely data collection and dissemination, in addition to ensuring access to health services. Except in cases such as the Breast and Cervical Cancer Screening Program, the State is not a direct service provider, but it is involved in ensuring access to care. The public health system also fosters population-based research to define the burden of cancer and improve prevention, early detection, and quality of health care and life. It also establishes and maintains partnerships and is responsible for planning and policy development.

Leading causes of death in Missouri are heart disease, cancer, stroke, and chronic obstructive pulmonary disease (COPD). Including diabetes (seventh leading cause of death), these diseases account for 70 percent of all deaths in the State each year.

Key Points

- In Missouri, cancer incidence rates are nearly identical for African Americans and whites, but mortality rates differ markedly. 1992 data show overall cancer mortality for African-American women is 35 percent higher than for white women, and cancer mortality for African-American men is 59 percent higher than that of white men. This pattern is consistent for lung cancer (both sexes), breast cancer, and prostate cancer. In the case of colorectal cancer, however, African-American women have a higher incidence rate than white women, but approximately equivalent mortality.
- While African-American and white women, both younger and older than age 50, have equivalent rates of initial mammography, African-American women are less likely to receive regular screening as guidelines recommend. The State conducted focus groups and a study to determine barriers to appropriate screening. Identified barriers included cost; inadequate insurance coverage; lack of transportation; lack of interest or mammography not perceived as important; inability to take time from work; fear of results, pain, or the test itself; lack of trust; racial prejudice; and lack of female physicians. Women in urban areas were least likely to return for screening, as were women who had not had a previous clinical breast examination (CBE). Other factors contributing to disparities in repeat mammography included older age, low perceived susceptibility to breast cancer, lack of information, and being African-American. However, race often is a proxy for other significant factors, including access, quality of care, distribution of services, patient compliance, lack of health insurance, and late or inappropriate treatment. The causes of these disparities require further investigation.
- The State has been successful in passing legislation to provide matching funds for screening and diagnosis support funds for the Breast and Cervical Cancer Control Project. Legislation also has been passed mandating insurance coverage for breast, colorectal, cervical, and prostate cancer screening, and for reconstructive surgery after mastectomy. Cancer case reporting has been extended beyond hospitals, and the State has long had regional cancer control coalitions.
- Like several other states, Missouri would benefit from more flexible categorical funding; currently, there is no funding for comprehensive cancer control. The Preventive Health and Health Services block grant has been used to fund cancer control, but it is being reduced.

Missouri also relies on donated services to fund treatment for abnormalities detected through national screening programs. Other identified needs are for better translation of research results into practice and strategies for getting information to physicians.

- Further research is needed on the availability and quality of needed cancer care in Missouri. The State seeks to continually improve its surveillance efforts and enhance cooperation between public health and university researchers and between data collection and program delivery.

MS. MARYANN COLETTI

Background

Last year, the Alvin J. Siteman Cancer Center served approximately 4,800 new cancer patients, of whom about 2,900 were Missouri residents. More than 40 percent of patients treated at the Center are receiving Medicaid, Medicare, or are uninsured and receiving care free of charge through the Barnard Trust Fund.

Underserved populations in Missouri include individuals with no health insurance or inadequate insurance; those with limited financial, physical, social, and emotional resources; and those with access limitations linked to rural residence, limited physical mobility due to age, inner-city transportation problems, and family and work responsibilities that limit access to or willingness to seek care. Vulnerable populations include the elderly; low-income working-class families; rural farm families; inner-city economically disadvantaged people; and cultural and racial minorities, including new immigrants.

Key Points

- In Missouri, the disconnect between research and the delivery of cancer care is tied to: (1) lack of insurance coverage for physician/provider-recommended treatment protocols; (2) lack of insurance coverage for necessary early detection and diagnostic tests; (3) lack of factual data that would enable the public to make informed cancer care decisions; and (4) the need to provide accurate, up-to-date cancer information to both the public and health care providers.
- People in Missouri are dying from treatable cancers because they are diagnosed with advanced disease; this typically occurs because of underutilization of existing early detection tests and the lack of effective screening tests for certain cancers (e.g., lung, ovarian). In addition, clinical trials are underutilized.
- Missouri has achieved a number of legislative and other initiatives to improve the cancer care available to residents. State legislation has been passed to provide coverage of early detection tests, and the legislation mandates that coverage will be adjusted over time to remain consistent with ACS guidelines. State legislation also mandates coverage for breast reconstruction following mastectomy. Legislation has been passed to expand case reporting to the State cancer registry. Local initiatives in tobacco control and clean indoor air have been established. Cancer screening is being delivered to economically disadvantaged populations through the Breast and Cervical Cancer Screening Project and other county health department initiatives. Neighborhood involvement, particularly among church groups, has helped residents access early detection tests and cancer control projects.

Recommendations

- Increased Federal funding is needed for: conducting research to reduce cancer mortality and morbidity; improving cancer reporting systems; facilitating a smoother transition of clinical trials results into standard practice; paying the cost of proven treatment protocols; promoting

community projects and programs that meet local needs; assisting community-based groups to implement proven cancer control interventions; supporting legislative mandates to improve cancer control outcomes, and ensuring protection of long-term survivors' rights.

- At the State level, Missouri needs to: assist local communities to implement realistic cancer control action plans; increase funding to help communities assess, develop, and implement proven cancer control interventions; protect long-term cancer survivor rights; and ensure the privacy of genetic information.
- At the local level, Missouri needs to improve the capacity to implement proven interventions and develop community collaborations to utilize all available skills and reduce duplication of effort.

DR. KELLY PENDERGRASS

Key Points

- In Missouri, regional differences exist in the likelihood that women eligible for breast-conserving surgery will receive this treatment instead of mastectomy. Rural women may choose mastectomy because the nearest radiation facility is two hours away by car. In addition, some may choose mastectomy because they feel more assured that they will not have a recurrence; education is needed in this regard. Some physicians in the State still believe that mastectomy is the preferred treatment for breast cancer.
- Many in the African-American community in Missouri have a fatalistic attitude about cancer and remain hesitant to participate in clinical trials because of the infamous Tuskegee experiments. These attitudes will be difficult to overcome.
- Most participants in clinical trials in Missouri are Caucasian, and results of these trials cannot necessarily be extrapolated to all populations.
- The Kansas City facility at which Dr. Pendergrass works takes subspecialty care to 12 rural communities outside of the city to reduce the geographic barrier to care and allow patients to receive chemotherapy and participate in clinical trials in their own communities. In Missouri, 30 to 40 percent of women with early Stage I breast cancer still have a recurrence and require systemic therapy. This approach helps make treatment available to all populations regardless of place of residence or economic means.
- Because Tamoxifen is administered orally, it is not covered by Medicare for the treatment of breast cancer. This drug may cost several dollars a day, and poor or uninsured patients may either not take the therapy at all or may reduce the dose, thereby receiving ineffective therapy. Some patients travel to Mexico to buy Tamoxifen because it can be purchased for 25 cents per tablet there, rather than the dollar per tablet at retail pharmacies in Missouri.
- Genetic testing is an issue in Missouri. The tests are not covered by insurance, so unless they are subsidized by a grant, many women who might benefit are unable to receive these services. Patients also are concerned that a documented positive test result will affect future insurability.
- Despite the findings of the Breast Cancer Prevention Trial demonstrating Tamoxifen's protection against breast cancer occurrence in the contralateral breast of women who had been treated for breast cancer, only 10 percent of the Missouri women who would benefit from this therapy are receiving it. The impediments to more widespread use of this therapy appear to be lack of insurance coverage and the out-of-pocket cost of the drug, as well as physician reluctance to prescribe Tamoxifen. Primary care physicians surveyed indicated that

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they hesitate to prescribe Tamoxifen because the therapy takes too much time, is nonreimbursed, causes side effects that must be dealt with, and poses a possible legal liability.

Recommendations

- Any reductions in Medicare reimbursement for cancer drugs must be offset by increases in payments to providers for the costs of administering cancer care. The proposed cuts in Medicare reimbursements will be devastating to community oncology practices, where most patients receive their care. Allowing these cuts to occur would signal an irreversible retreat in America's war on cancer and would be tragic for seniors who come to community oncologists for care, survival, and hope.

DR. DAVID OTA

Background

In addition to his work as a practicing surgical oncologist, Dr. Ota serves on the NCI subcommittee that reviews the NCI-funded Cooperative Groups that conduct clinical trials in the United States, as well as similar groups in Canada and Europe. In addition, he serves in the NIH Clinical Oncology Study Section, which reviews clinical research proposals.

Key Points

- Education of both patients and health care providers is a critical element of the current disconnect between research and delivery. In rural, predominantly white Missouri, many residents feel the same mistrust of the medical system and of clinical trials as has been observed in African-American communities. There is a need to better explain the clinical trials mechanism and describe progress that has been achieved as a result of trials. Patients need to be assured that safety mechanisms are in place. Unfortunately, the media tend more often to highlight problems that have occurred in clinical trials, and less so the successes.
- Distance from sources of cancer care is a major barrier to care for people in rural areas. In urban areas, distances are shorter, but traffic congestion and transportation problems still make distance from care a barrier.
- A mobile mammography van has been outfitted with high-quality equipment and provides services throughout the State. However, it costs \$200,000 per year to operate and generated only \$50,000 in revenue last year. To help cover the costs, corporate sponsorship is being sought, although the administration of the hospital has concerns about this approach.
- Proposed Medicare reimbursement cuts may reduce the amount and quality of care provided by oncologists through satellite clinics in rural areas and may reduce the availability of clinical trials to rural patients.

Recommendations

- Physician education is needed concerning the value of trials. Additional funding is needed to include education about trials in academic surgical training programs.

MS. JUDY BENTLEY

Background

The African-American community (approximately 23,000 families) served by Ms. Bentley's program has an unemployment rate four times the national average. Sixty percent of patients are uninsured or underinsured, and generally are unable to pay for health services. The Program has established

collaborative relationships with St. Louis University and Washington University in St. Louis that help to develop the Program's services and get them to the population. The Program also collaborates with a large area hospital that provides mobile mammography services six times per year as well as any followup care required for women with abnormal findings.

Key Points

- To help patients access care and retain them in the system, the Program uses a service integration approach. Many of the services offered are volunteered by physicians, nurses, and other professionals. The services provided include health, education, and community outreach. The outreach program is aggressive and includes primary care to help get people into the system so that education and screening can take place in addition to addressing patients' initial complaints.
- Collaboration with the large area hospital has been empowering for the community. To persuade women to take advantage of the mammography services, however, repeated education was needed to overcome myths and misconceptions about mammography and breast cancer. About 75 percent of women are returning for repeat mammography and are bringing their partners in for prostate screening.
- Effective education in the community requires cultural sensitivity, sensitivity to varying literacy levels, and common sense. One-to-one contact, often in the home, is essential to success.
- Health must be marketed with the same tenacity as commercial products. For example, in addition to repeated teaching, the Program ensures that the facility is clean and attractive, because people will want to come back and will refer friends.
- It also is crucial that people are treated with dignity and respect, regardless of their ability to pay for services. If they are not, they will be lost to prevention and screening efforts and are far more likely to present later with advanced disease.
- The Program also provides transportation services for women with abnormal mammograms, because the hospital is 20 miles away.
- Because of the success of the Program's network system, it has been asked to participate in a grant to develop and evaluate prostate cancer screening services.

DISCUSSION—STATE OF MISSOURI

Key Points

- In some cases, patients refuse to enroll in clinical trials because they do not want to be randomized to the standard treatment arm of the study. Some physicians, believing the experimental treatment to be superior, will then provide this care outside of the trial. Such action is counterproductive to the purpose of clinical trials, which is to provide rigorous evidence as to the benefit of a new treatment or other intervention. Physician education on this issue is needed. In addition, physicians can bias patient choice with their body language or choice of words in describing the trial or treatment options. Patients are extremely sensitive to these signals. Physicians and medical school students also need training in how to present information about clinical trials and standard treatment options to patients.

- In some cases, the word *protocol* is used to imply that the patient will be on a clinical trial, when, in fact, the word is being used as a marketing tactic by oncology specialty groups that have an affiliation with the NCI.
- It was suggested that the number of patients enrolled in clinical trials might be used as an outcome measure for physicians or physician groups.
- Concern was expressed that industry-sponsored clinical trials, which are more lucrative for participating physicians and institutions, may be less objective or may suppress information about negative findings.
- Trials need to be simplified, and reimbursement increased, to encourage community oncologists to enroll patients.

DAY ONE CLOSING REMARKS—DR. FREEMAN

- Much progress against cancer has been made since the inception of the National Cancer Program in 1971, but despite this progress, some populations with cancer still do less well. Though these populations can be defined in many ways, a common factor often is poverty, which affects people of all races and geographic locales. Poverty results in social circumstances related to less information, poor living conditions, risk-promoting lifestyles, and lack of access to preventive care. We know that the way people live—their lifestyles, attitudes, and behavior—influences what diseases they develop and how they respond when they have a disease. But we need to improve our understanding of these factors and how they affect disease outcome.
- Not everyone has access to the existing health care system. Currently, 44 million people are uninsured, and this number is rising. The move to managed care has resulted in managed cost at the expense of indigent care, research, and training. In addition, Medicaid funding has been cut, exacerbating the fact that in a Nation with the greatest medical care system and technology, some people are unable to get the best possible care, or any care at all. The reasons for this situation—including poverty, culture, and social injustice—are the issues to be explored in this meeting.
- Recognizing the diversity of the Nation, the Panel will hear from every State in the country on these issues. The Panel hopes to identify both universal issues and those that affect only specific regions or populations. Its report will be delivered directly to the President of the United States.

JUNE 16, 2000

OPENING REMARKS—DR. HAROLD FREEMAN

Dr. Freeman opened the second day of testimony by providing a brief history of the National Cancer Program (NCP), indicating that:

- In 1999, the Panel heard testimony on the history, evolution, and current status of the NCP for the purpose of understanding how the NCP has arrived at its current state of operation and emphasis, and how its course might be modified in the future to best serve the American public. The Panel defines the NCP as extending broadly from basic research (the engine for discovery) to translational research, to applied and population research—including cancer control—to the application of research findings in routine cancer care. The principal finding from the testimony presented last year is that a disassociation exists between the discovery

and delivery enterprises in this country. These two equally important components of the NCP are funded differently—a problem whose impact needs to be better understood.

- The current series of meetings is designed to look more deeply into the problems faced by communities across America with respect to access to care, particularly raising the question of whether the Nation has fairly applied its discoveries to all populations, regardless of economic status, culture, and other demographic factors.
- Currently, 1.2 million new cases of cancer are diagnosed annually, and more than a half million people die each year from cancer; each day, 1,500 lives are lost to cancer. Thus, cancer remains a devastating national problem. The annual cost of cancer is estimated at \$107 billion annually, of which \$37 billion is direct medical expenditures. The population is aging and is living to older ages; this is important because cancer occurs primarily in older individuals. The population also is becoming increasingly more diverse, as new immigrant populations bring with them their cultures, languages, communication patterns, belief systems, values, traditions, world view, lifestyle, attitudes, and behaviors. All of these factors must be taken into account in developing and providing cancer care services.
- In addition, the health care system is changing. Pressure to contain health costs has resulted in some loss of financial support for clinical research and has had a disproportionate effect on the underserved. Fewer revenue dollars are available for hospitals to use to support care of the medically indigent. Medicare and Medicaid funding to both institutional and individual providers has declined.
- More than ever, we realize that the burden of cancer is borne unequally throughout our population. There are those in America who receive cancer care unparalleled in the world, while others suffer increased cancer incidence, mortality, and lower survival. These populations can be defined many ways, but economic status is a key factor in who receives appropriate care and who does not. Regardless of race, poor people have the highest cancer death rates and lowest survival from cancer. At the same time, race is itself a factor, as are cultural differences. In the past decade, approximately a dozen studies published in peer-reviewed journals have documented unequal medical treatment according to race.
- Whereas in 1971, the Federal Government was the primary source of cancer research funding, today only about 60 percent of research funding comes from Federal sources; of that amount, less than half comes from the NCI. The biotechnology and pharmaceutical industries have become major funders of cancer-related research, a source of some concern since commercial concerns by definition have a profit orientation. Many of the most important research questions that need to be answered are not those that will generate a profit.
- We now know that cancer is more than 100 distinct diseases with diverse treatment requirements. Emphasis on the role of tobacco in cancer has increased significantly since the 1970s, with multiple lawsuits underway nationally to recover costs of treating tobacco-related illnesses.
- The Panel concluded that a critical disconnect exists between the discovery system and the delivery system that has not previously been well described. This problem, and the equal importance of these two principal components of the national cancer effort, must be recognized and addressed. The delivery component encompasses primary and secondary prevention, cancer control, education, and access to high-quality, evidence-based care. Like the research enterprise, it is composed of many and diverse stakeholders. In addressing delivery issues, there continues to be a tension between individual-centered approaches and those that are population-oriented.

- The research system has been successful and should continue to be fully supported. More research funding is needed for population and behavioral studies that will enable us to better serve groups that currently are not receiving the best possible care. The Panel believes the budget of the National Institutes of Health and NCI should be doubled over the next five years.
- At the same time, we must recognize that we have attempted to solve access and delivery problems with research solutions. We cannot win a war against cancer without delivering discoveries to the American public. Like the “smart” bombs used in the Persian Gulf war that delivered weaponry to the places the enemy was invading, we must deliver cancer interventions to the neighborhoods in which the disease is attacking and killing the most people. In 1998, the President of the United States declared that the disparities in health outcomes experienced by black and white Americans must be eliminated. The war against cancer has to date been largely a research war, but research is not enough. Discoveries must be delivered to all Americans, regardless of their socioeconomic status and culture. Access and delivery issues have not been adequately addressed. It is unrealistic to ask research institutions to answer for the results of inadequate application and delivery of interventions developed from research findings.
- Health outcomes, quality of care, and lifestyle issues must receive more emphasis. In addition, certain sectors or groups in the Nation do not perceive themselves as having a role in the national cancer problem. These include agriculture (e.g., support of tobacco farming, pesticide use), the media (e.g., glamorization of tobacco use), and commerce/trade (e.g., tobacco exports). To date, we have not addressed the cancer problem with an approach that acknowledges all of the relevant issues and players. The public has a role in recruiting these sectors and groups to the national cancer effort.
- The cancer problem is not just a scientific and medical issue, but a moral and ethical issue as well. In a country with the most advanced technology in the world, we have populations living in Third World conditions. We must mobilize the public and political will to sustain a full national effort against cancer.
- Legislators and policymakers have a role in removing the barriers to care that have caused many of the health disparities that now exist. Health care payers of all types need to accept sound research evidence of the benefit of new interventions and provide coverage for them. Mechanisms are needed to ensure that payers have access to and understand this evidence.
- Culturally appropriate education is needed to make health professionals and the public more aware of the cancer problem and current knowledge about prevention and all aspects of care. The current and future cancer workforce—researchers and care givers—requires greater training in state-of-the-art cancer prevention and care; this workforce also must become more representative of the diversity of the Nation and more sensitive to cultural issues relevant to specific populations.
- If we do not better connect the research and delivery enterprises, the Panel believes that our progress against cancer will continue to be slow, uneven, and incremental. In all of our efforts against cancer, the public must benefit.
- The Panel recognizes that much of the testimony it will hear over the next 18 months will be anecdotal, but expects that in the aggregate, the testimony will illuminate problems that cross-cut the Nation, as well as those that are specific to various regions and populations. Moreover, in creating political change, nothing is more powerful than the voices of real people describing real problems.

STATE OF IOWA

Presenters:

Dr. Cassandra Foens

Dr. John Okerbloom

DR. CASSANDRA FOENS

Key Points

- Getting information about research results to physicians is a relatively minor problem. The American Society of Clinical Oncology (ASCO), the American Society for Therapeutic Radiation Oncology (ASTRO), and the American College of Surgeons all conduct large, well-attended annual meetings devoted to discussion of new research. The National Comprehensive Cancer Network (NCCN) continues to publish treatment guidelines for many of the common malignancies. In radiation oncology, the American College of Radiology and the Radiation Therapy Oncology Group continue to conduct patterns-of-care studies that show how patients with common malignancies are being treated around the country. Other groups also are active in assessing and publicizing patterns of and advances in care.
- Access, particularly in rural areas, is a major issue. Access issues are local issues that respond best to local solutions. For example, Iowa has about 20 radiotherapy facilities, most of which are in the larger communities. This is probably an appropriate number of facilities relative to the population's size, but the distribution of the facilities means that rural patients must drive considerable distances to receive services. Since radiotherapy cannot easily be transported to the patients, a free van service has been established by the hospital to go to small communities and bring patients to the hospital for treatment. Because of costs and liability concerns, such services are not available everywhere, but transportation services such as this are important with an increasingly elderly population. Many elderly rural patients (especially older women) either do not drive, fear driving in the city, or have treatment side effects that prohibit driving.
- The major impediment to bringing research findings to the community is the powerful emphasis on cost reduction (not just cost containment) in medical care. Since cancer is overwhelmingly a disease of older people, the primary payer for cancer services is Medicare. Once Medicare develops reimbursement policies, most commercial insurers follow suit.
- The recent Executive Order requiring Medicare to pay routine patient care costs for those on clinical trials is good news, but new pressures are being placed by Medicare on hospitals for the technical (nonphysician) costs of delivering radiation therapy. These costs include wages paid to technical personnel, equipment purchase and maintenance costs, and supplies. Radiation oncology is highly dependent upon technology. The equipment is expensive and must be updated continually if it is to deliver the treatments that clinical research proves are best. The average cost of a linear accelerator, for example, currently is close to \$2 million; a treatment simulator costs approximately \$800,000; and treatment planning hardware and software costs about \$100,000. This equipment all has a limited useful lifespan before becoming obsolete.
- Brachytherapy and intensity-modulated radiotherapy are two of the newest technologies showing promise in clinical research. These highly conformal treatments have additional associated costs for equipment, radioactive sources, personnel, and treatment planning systems. These costs do not vary appreciably from region to region, yet Iowa ranks 48th of the

50 states in the rate of Medicare reimbursement to hospitals per capita. This reflects an assumption that it is cheaper to deliver services in Iowa than in New York, but it costs the same amount of money for facilities in Iowa to purchase a linear accelerator as it does for those in New York. With the imminent implementation of the Medicare Ambulatory Payment Classifications (APCs, also known as the Hospital Outpatient Prospective Payment System, or HOPPS), reimbursements to hospitals for current and newer technologies are being cut even further.

- To illustrate the impact of the APCs/HOPPS, high dose-rate brachytherapy, which a few months ago was being reimbursed at \$760 per application, will now be reimbursed at \$380 per application. The equipment needed to perform this service costs at least \$350,000, and every four months, the radiation source must be replaced at a cost of \$35,000, even if the machine was unused. Similarly, conformal beam and intensity modulated therapy, simulation, and treatment planning currently are “bundled” and reimbursed at about \$1,000; this is being cut to \$670. In addition, support for medical physics (crucial to patient safety in radiation oncology) performed by Masters- or Ph.D.-degreed professionals is being cut from a weekly reimbursement of \$112 to \$64. At rates such as these, hospitals cannot continue to invest the amounts of money it takes to provide cutting-edge radiation therapy proven in clinical research to be better for patients. These reimbursements scarcely allow hospitals to maintain current technology. In the Midwest, where reimbursements historically have been lower than in other regions, the declining reimbursement levels could be catastrophic.
- Clearly, medical spending has been increasing at what is considered to be a significant rate. However, even the most costly cancer therapies might be cheaper in the long run if they were more effective, resulting in fewer failures and more cures. All of the clinical research in the world will be of no use to patients in the Midwest if their hospitals cannot afford to own the equipment and pay the personnel needed to delivery these high-tech, labor-intensive treatments safely and efficiently.
- In the Waterloo, Iowa, area, Dr. Foens and colleagues have been providing free prostate cancer screening. They have attempted, with little success, to persuade family practice physicians and internists to volunteer four hours per year to conduct these screenings for the underserved in the area. A similar problem exists in trying to provide free skin cancer and head and neck cancer screening.

Recommendations

- Cost issues should not be allowed to deteriorate the excellent safety record of radiation oncology that derives from its extensive use of medical physics.
- Current bills in Congress mandating private insurer payment for proven screening studies should be supported, but more funds are needed to provide treatment for detected abnormalities.
- There is a need to get better staging tools, such as Positron Emission Tomography (PET), into communities to improve treatment decisionmaking. The current bill in Congress to establish an NIH Institute for Biomedical Imaging should be supported.

DR. JOHN OKERBLOOM

Background

Iowa’s population numbers over three million people, yet the State is relatively small compared with other Midwestern states and has no major metropolitan areas. Des Moines is the largest city. Omaha, Nebraska

However, the University of Iowa is world-class in many ways and has endeavored to develop a cadre of physicians for Iowa communities.

Key Points

- Because physicians are less willing in the current health care economic climate to volunteer their services, some of the problems of providing service to the underserved may have to be resolved using nonphysician personnel. The program described by Ms. Bentley illustrates how local people can devise solutions to local problems.
- In Iowa, many of the problems in translating research findings into routine practice are due to lack of time and reimbursement for preventive measures, not lack of knowledge on the part of primary care physicians. As in many States, medicine in Iowa focuses on acute rather than preventive care. Significant opportunities are being missed to promote prevention in a variety of important areas when people access health care for a specific problem.
- We need to do a better job of getting accurate information to patients. Advertising by pharmaceutical manufacturers has raised the visibility of certain medical problems, but patients sometimes misunderstand or draw unwarranted conclusions from newspaper articles or other information they receive.
- Iowa's rural population is older, tends to be fairly pragmatic about most matters, and often is fatalistic concerning disease.
- Hospitals thus far have learned how to survive with the Federal Government health care payment systems, but the new APC reimbursements may be particularly detrimental to outreach services provided by medical oncologists and other physicians. Mobile mammography and mammotome biopsy services may likewise be curtailed. One rural hospital has begun charging rent to the urban physicians who come to the area to provide care. Local physicians, while interested in new approaches and research, are more concerned with addressing daily crises.
- Men, especially rural men, are a difficult population to reach. They tend not to be knowledgeable about health issues, do not believe they need care, and put off screening and care they know they should have.
- Because of inadequate or no reimbursement, even preventive measures like Tamoxifen use are not employed because of the time required to explain the benefits and risks of the therapy to the patient.
- It may be advisable to leave the promotion of screening guidelines to nongovernmental, nonphysician organizations, such as the ACS.
- Changing high-risk behavior is extremely difficult, as illustrated by the high rates of smoking among well-informed groups, such as youth and nurses.
- In Iowa, the poorer the county, the poorer the screening rate. Especially in the rural counties, people are unwilling to travel to receive care, and it is difficult to take the care to them.
- One reason people are dying of preventable cancers in Iowa is that while primary care physicians know that the relevant information exists, they are unable to translate it into their daily practices. Brochures, while plentiful and distributed regularly, are ineffective; they are written at too high a reading level for many patients and are an inappropriate way of transmitting information for many others.

- There has been little coordination of effort or sharing of effective practices or equipment among small towns surrounding Council Bluffs. This situation is improving slightly.
- Health care for the homeless as an issue is essentially ignored; care is provided on a case-by-case basis.
- From an economic perspective, there is a significant disconnect between palliative care and hospice care; this transition is difficult for patients and physicians alike. The hospice system is now for-profit and driven by rules and regulations; as a result, palliative care such as a course of radiation or chemotherapy that would help manage pain or other symptoms often cannot be provided.

DISCUSSION—STATE OF IOWA

Key Points

- Nurse practitioners and nurses are underutilized in primary care practices where they could be performing cancer risk assessments and early detection tests. However, fee-for-service physicians are only reimbursed for the services they themselves provide; any risk assessment or similar services provided by nursing personnel are unreimbursable. This lack of payment for nonphysician services is a barrier to better care. As community physicians in clinics and private practice see reimbursements decrease each year, education is one of the services that often is sacrificed to keep the clinic or practice afloat. It was agreed that many screening tests could, and perhaps should, be done by nonphysician personnel; in addition, if these personnel perform a higher volume of such tests than the physician, their level of expertise will likely be greater.
- Since cancer care is still research-oriented and evolving, Medicare should make some exceptions in its reimbursement policies for cancer care relative to its reimbursements for the care of other diseases. Alternatives for solving Medicare reimbursement issues include: raising the age of eligibility for the program, increasing beneficiaries' share of costs, and establishing a lifetime fund that would relieve some of the Medicare expenditure burden.
- Medicare will pay internists whatever they ask for diabetes management and do not require adherence to any guideline. In cancer, treatment must be provided according to guidelines and well-defined research protocols, but oncology care reimbursements continue to be cut and claims denied. For example, under the new APCs, reimbursement for a diagnostic mammogram will be less than for a screening mammogram, because payment levels for the latter were set by statute and cannot be changed.
- Lack of consensus on screening guidelines (e.g., mammography) is a barrier to better care, since many primary care physicians do not know which recommendations (e.g., NCI, ACS, American College of Obstetrics and Gynecology) should be followed. Reimbursement policies that are inconsistent with respect to recommended screening intervals discourage patients from getting appropriate care.
- The areas adjacent to the Platt River are known as the "lymphoma belt." It is not known whether herbicides and/or pesticides from the farm areas or other environmental influences are contributing to the high lymphoma incidence and mortality of populations living near the river or drinking its water. The NCI and Environmental Protection Agency (EPA) do not seem to be adequately involved in determining the source(s) of the problem.

- Iowa also has an excess of brain tumors; the Farm Health Study is now underway to study the types and levels of farm chemicals in the area to determine what their effect may be on this problem. Data from the Iowa SEER registry are being used in this study.
- Medicine has become a victim of its own success. People think that medicine can overcome any and all lifestyle abuses and their consequences.

Recommendations

- From a cancer prevention standpoint, the most important thing the Federal Government can do is to change policies that make it easy and acceptable for people to smoke.
- Federal funding should more heavily emphasize prevention compared with treatment strategies. Though there are concerns about the involvement of the pharmaceutical industry in drug development, one strategy might be to allow private industry to concentrate on treatment, while the government focuses on prevention. Big business is not interested in prevention unless it can be shown that, for example, getting employees to quit smoking will decrease health care expenditures. There is no economic drive in society to prevent cancer, so leadership in this area is needed.
- More emphasis is needed on better and more intelligent screening. We have made no progress in lung cancer because we do not have a screening tool that enables us to find cases early enough. Conversely, breast carcinoma *in situ* is now routinely diagnosed and treated, never progressing to invasive disease; similarly, many cases of cervical dysplasia are identified and treated, never progressing to invasive cervical cancer. Improved screening tools and increased use of them have contributed to these advances.

STATE OF OHIO

Presenters:

Ms. Lois Hall

Mr. Robert Indian

Dr. Nathan Levitan

Ms. Jill Wagner

MS. LOIS HALL/DR. MOON CHEN

Background

Ms. Hall first read into the record a letter from Dr. Nick Baird, Director, Ohio Department of Health. Among other points, Dr. Baird noted in his letter that Ohio is a large and diverse State in terms of its population and geography. Ohio is fortunate to have seven medical schools, two NCI-designated Comprehensive Cancer Centers, several public health education programs, and many excellent public and professional voluntary health organizations. He pledged Ohio's support of the Panel's recommendations resulting from the current series of regional meetings.

Ms. Hall then read into the record the testimony of Dr. Moon Chen, Division of Health Behavior and Health Promotion, Ohio State University, who was unable to attend due to bad weather and airline cancellations.

Ohio is the Nation's seventh largest State, and in many respects (e.g., political, commercial) is a bellwether for the rest of the country. The State has highly diverse geography and a mix of major urban

centers and large rural areas. As much as 50 percent of Ohio is rural; one third of its 88 counties are Appalachian, one of America's poorest regions.

As in other States in the Midwest, whites constitute the largest single racial group in the State; however, they are not a homogeneous group. The Appalachian white population constitutes only 10 percent of the State population but has a high cancer burden and is disproportionately affected by heart disease. Smoking rates are high among this population. Similarly, Ohio is close to Kentucky—both geographically and in terms of its male smoking prevalence rate. Ohio also is home to an Amish population of approximately 30,000, who are very difficult to reach with health messages or health services.

African Americans constitute the largest population group in Ohio; their cancer profile resembles that of African Americans in other states—women have a lower cancer incidence rate but a higher cancer mortality rate than whites. African Americans make up much of the urban poor population.

Hispanics comprise a major proportion of the migrant workforce of Ohio. Their exposure to farm chemicals is higher, and their access to consistent health care—let alone cancer control—is much less than that of other populations.

Ohio also has a significant population of Native Americans; as in other areas of the country, providing cancer control services to this population is a challenge, particularly concerning cultural views of tobacco use. Asian and Pacific Islanders are Ohio's fastest growing population. Cancer, not cardiovascular disease, is the leading cause of death in this population.

Ohio's fastest growing populations are racial and minority populations and those that historically have been medically underserved or unreached.

MR. ROBERT INDIAN

Background

The mission of the Ohio Behavior Risk Factor Surveillance System (CDC funded) is to provide high-quality data and analyses to identify high-risk populations with health behaviors that increase the risk of disease and adverse physical conditions and injuries, and to support the evaluation of interventions to prevent disease, adverse physical conditions, and injuries.

The mission of the Ohio Department of Health is to protect and improve the health of all Ohioans by preventing disease, promoting good health, and assuring access to quality health care.

Key Points

- Mr. Indian's office, which performs community cancer assessments for the Ohio Department of Health, receives frequent calls from residents who believe the incidence of cancer in their neighborhood is unusually high. Since lifetime cancer incidence rates in the State are approximately the same as those of the Nation (one in two men and one in three women), they are usually correct, but often not for the reasons they may suspect. A huge gap exists between what the public perceives are the major causes of cancer and what scientists believe are the major causes.
- Diet and nutrition may be responsible for about 35 percent of cancer deaths. Tobacco use is responsible for about thirty percent of cancer mortality, including about 85 percent of lung cancer deaths. Reproductive and sexual behaviors are believed responsible for approximately seven percent of cancer deaths. Occupational hazards cause about four percent of cancer

deaths; excessive alcohol use about three percent; excessive sun exposure, around three percent. Farm chemicals are believed to cause about two percent of cancer deaths. Industrial products, food additives, and medicines and medical procedures each are responsible for about one percent of cancer deaths. Other causes are responsible for 13 percent of cancers. These figures are important for the public to know because they show that the individual has a great deal of control over whether or not he or she develops cancer, and that if they do, the means exist to find it early.

- In Ohio, smoking is more prevalent among those with lower household income and lower educational attainment. In addition, obesity-related cancers (e.g., colorectal, prostate) are most prevalent among those with lower educational attainment and lower household income. Sedentary lifestyle is highly prevalent in Ohio and is associated with cigarette smoking and overweight. Those with sedentary lifestyles also tend to have lower incomes and lower educational attainment. These same groups are least likely to consume five servings of fruits and vegetables per day.
- Ten percent of Ohioans aged 18 and older have no health insurance. Among those with less than a high school education, over 15 percent have no insurance, and among those with less than \$20,000 income, the uninsured rate is 21.2 percent.
- Higher income is a predictor of the likelihood that a woman has had a recent mammogram, though there is little difference by educational level. Income and education are predictors for Pap smears, but the data for colorectal screening do not follow this pattern for undetermined reasons.

Recommendations

- High-quality surveillance data are needed to enable the identification of high risk groups, to focus program planning, and to evaluate prevention and control efforts.
- Theory-based education programs at the community level are needed to empower residents and provide information on the primary causes of cancer and prevention and early detection strategies.
- Surveillance systems and all prevention and early detection programs should be evaluated to ensure that they are effective.

DR. NATHAN LEVITAN

Key Points

- Once research has identified the treatments associated with the best outcomes, and once patients have access to physician care, the next question is whether health care providers are actually delivering the best possible care (i.e., what is the quality of care?). Relatively little data exist to make this assessment. A 1999 Institute of Medicine (IOM) report suggests that nearly 100,000 deaths may be occurring annually as a result of medical errors. In addition, there is considerable variation in the practice of medicine nationwide; this variation is a red flag for concerns about quality.
- It has been shown, for example, that complication rates are reduced when complex procedures (e.g., thoracotomy for lung cancer, pancreas resection for pancreatic cancer, prostatectomy) are performed at facilities that do a high volume of such procedures. Variations in practice also have been documented in radiation therapy, surgery, and other medical care for cancer.

- The Rand Corporation has recently initiated a study of quality and variations in care and outcome for early-stage breast and colon cancer patients in Cleveland, Houston, and Los Angeles. These diseases were selected for study because of the availability of numerous Phase III study reports documenting the most effective known treatment interventions. Medical records of patients from diverse socioeconomic backgrounds will be reviewed to collect data on treatment received and outcome. Clearly, however, more data are needed pertaining to inpatient and outpatient cancer care of all types, including surgical outcomes and primary care physician compliance with screening recommendations. Currently, the only surveys of practice patterns are those sent to practicing oncologists. Chemotherapy errors are known to occur, but their magnitude and frequency are unknown. We also do not know the extent to which patients receive needed psychosocial intervention after a cancer diagnosis, nor do we know the type of nutritional services they receive.
- In the manufacturing industries, customers define quality; manufacturers set standards; and there is an ongoing process of measurement, data analysis, and modification of processes resulting from scrutiny of the data. In addition, financial incentives drive quality measurement and improvement. In health care, we do not really know how to define quality; care paths only recently have been written, and there has been little measurement of compliance with these guidelines in various delivery settings. Little feedback is provided to physicians concerning their own practices. Moreover, unlike in industry, it is harder to show the return on investment for a continuous quality-improvement program in medicine. At this time, there are few sources of funding to measure and improve the quality of cancer care.

Recommendations

- A continuous quality-improvement program is needed in cancer care that considers physician compliance with standards, measures procedure-related morbidity and mortality (for surgery, chemotherapy, and radiation), and collects and assesses patient feedback and satisfaction. For such a program to be effective, proven interventions must be implemented.
- The President's Cancer Panel should advocate for funding to measure the quality of cancer care as it is practiced across the country.

MS. JILL WAGNER

Background

Ms. Wagner related that in being rerouted in her air travel to the meeting, she found herself seated next to an anxious young man in need of information about breast cancer; he was traveling to be with his mother, who was about to undergo mastectomy and reconstructive surgery. A cancer survivor herself, Ms. Wagner observed that cancer has taught her to treasure each moment, to value family and friends most highly, to be flexible and resilient, and to view each deviation in day- to-day life as an opportunity to experience new things, meet new people, and, perhaps, make a difference in another person's life.

Key Points

- Soon after she began work four years ago in the CDC Breast and Cervical Cancer Screening Program of Midwest Ohio, Ms. Wagner encountered a patient who was so fearful of hearing the word *cancer* that she allowed a growing breast lump, weight loss, increasing pain, and other symptoms to go untreated for many months; this decision cost the patient her life. This level of denial due to fear is not uncommon among women across Ohio, including those in the Appalachian region, the inner cities, rural areas, and the Amish community.

- Fear of cancer includes fear of the disease itself, fear of not being able to access care, fear of the expense of cancer care and taking on debt that might be left for families to repay, and fear of cancer treatment. Also, some senior citizens are embarrassed to discuss symptoms.
- Families are confused by the volume of conflicting information about cancer and cancer prevention. Many families have no source of comprehensive health services.
- Fear could be overcome by information and education at national, regional, and local levels that provide clear guidelines as to what people can do to reduce their risk for cancer. Education also should emphasize survivorship. People must be taught to minimize their fear and to become champions in their own battles for survivorship.
- Health care in this country is focused on fixing problems rather than on promoting wellness. In addition, the fragmentation of care often delays the delivery of state-of-the-art treatments to those who are diagnosed. Cancer patients without health insurance may have limited treatment options.

Recommendations

- The focus of health care in this country should be changed from acute care to prevention and wellness. Since efforts to provide universal health insurance in America have failed, accessible community wellness centers should be established to serve families. Such centers would charge based on ability to pay, would receive a combination of Federal, State, and community-based funding, and would focus on teaching families how to become and remain healthy. Staffing would include health care professionals as well as case managers who would be responsible for patient advocacy, ensuring ongoing evaluation and timely screening and treatment services. In addition, the centers could provide smoking cessation, nutrition, and other educational and supportive services. The centers also would establish partnerships with other community resources.

MS. LOIS HALL

Key Points

- Perhaps the best aspect of the Ohio Breast and Cervical Cancer Project was its inclusion from the outset of a strong case-management component.
- Misinformation, confusion, fear, and pessimism about cancer remain significant among the public—and even among some providers. Individuals and providers also may have competing priorities that keep cancer from being a top concern. Women may have to choose between providing lunch money to children and paying the copayment for a mammogram; physicians may have to choose between assessing a patient's risk for non-cancer diseases and cancer in the limited appointment times allowed by health plans. Patients are overwhelmed by insurance claim-related paperwork and medical bills, not knowing who to call for information, and trying to understand the implications of a positive test result and treatment options. Some choose to avoid care because the information and processes are too difficult.

Recommendations

- It is time for the Nation's public health workforce to accept its responsibility for providing leadership and coordination in the war on cancer at the national, State, and local levels. Although the efforts of voluntary groups have been invaluable, they cannot do the job alone. The public health workforce is the legion of field troops that must join the fight against

cancer. These State and local staff should be the hub of the wheel in their communities, linking those in need with the resources available.

- To beat cancer, we must not only fight back, but we must strike first with prevention and early detection. We also need to convey a message of hope and confidence that the war on cancer can be won on all fronts for all communities. We need to use the return on the investment made in research to support our communities, clinicians, and voluntary organizations with public health leadership and coordination.
- A representative of the CDC's cancer program should travel with the Panel during this series of meetings to hear expressed the need for strong public health leadership in cancer.

DISCUSSION—STATE OF OHIO

Key Points

- Before quality of care can be assessed effectively, it must be decided what outcomes should be measured, and measures of those outcomes must be determined and validated. In cancer, mortality is not a particularly useful outcome because a large number of patients must be monitored for any given intervention to detect a difference in mortality. Preferred outcome measurements in cancer care probably pertain to patient satisfaction (with their own care, access, and communication with health care providers); provider compliance with interventions shown to reduce mortality; and morbidity associated with major interventions, procedures, surgery, and chemotherapy. It was observed, however, that similarities in mortality when treatment differs can raise important questions about the efficacy of specific interventions.
- The public does not appear to be ready to accept evidence-based medicine (i.e., people want what they want despite the evidence). This unwillingness is the basis of the current debate about prostate cancer screening and was at the heart of the controversy about mammography screening for women in their forties. Health care providers are important educators of the public, but the evidence on advances must be communicated to them clearly for them to succeed in this role.
- Patients have different perceptions of quality than do health providers or regulators; many patients judge quality on the cleanliness of a facility and the friendliness of staff. They may not know or care about the parameters of quality (e.g., facility certifications) that matter most to providers and regulators. This difference complicates quality measurement. It was noted that the results of a study of cardiac bypass surgery outcomes in New York State that were published in the newspaper had no effect on patients' choice of provider for this care. Other studies indicate that patients as medical consumers are not necessarily capable of selecting practitioners based on their compliance with state-of-the-art interventions and treatment guidelines. This does not, however, minimize the importance of patient satisfaction as a quality-of-care endpoint, although it certainly is not an exclusive endpoint. Patient satisfaction with access to care, handling of financial issues, communication with health care providers, pain control, and other quality-of-life issues are important outcomes that should be measured. It was noted that varying levels of patient recall and patient candor also complicate collection and evaluation of quality data.
- Medical records reviews conducted in the course of a study can be highly labor- and time-intensive depending on the source of the records; those in major institutions tend to be computerized and relatively easy to sample, while those in primary care settings tend not to be computerized and are much harder to sample randomly. In addition, primary care physicians have concerns about the confidentiality of the study and whether they will be

punished if their compliance is found to be lower than the standards being proposed in the study. These problems illustrate the difficulty in obtaining data on quality of care. To address these issues, the Harvard-Rand study will obtain patient consent forms from every individual and work with the institutional review boards of every participating hospital.

- The importance of navigators and others who can provide information to patients and populations at the community level and one-to-one was underscored. Messages must be delivered multiple times before understanding is clear and behavior is affected; messages must be reinforced to maintain behavior changes.
- Patients need better information to defuse fears about cancer treatment so they will be more willing to seek care and to participate in clinical trials.

STATE OF KANSAS

Presenters:

Dr. Sue Min Lai

Ms. Jackie Shaver

Ms. Peggy Johnson

Ms. Claudia Wojdylak

Dr. Claudia Perez-Tamayo

DR. SUE MIN LAI

Background

Kansas is a large rural State with 105 counties and a total population of 2.7 million. The majority of Kansans live in two metropolitan counties that, due to population density, have the hospitals with the most comprehensive oncology services. Other counties have as little as a single hospital with two to five beds; others have no hospital facilities at all.

By the Federal definition of underservice, 55 of 105 Kansas counties (55 percent) are either underserved or critically underserved for primary care. For specialty care, including many oncology services, these numbers are even higher; they have not improved since 1995 and are unlikely to do so in the near future.

Data from Kansas' recently rebuilt cancer surveillance system suggest that cancer incidence in Kansas is similar to rates observed in rural SEER states such as Iowa.

Key Points

- Cancer surveillance is critical to effective cancer prevention and control. While most cancer cases in Kansas are captured by the system, it is estimated that 10 to 12 percent of cases in underserved areas are not identified. Poor data in these areas make it impossible to identify high-risk individuals for screening or to conduct prevention and control efforts.
- Among the underserved in Kansas, more cancer cases are diagnosed at later stages or are unstaged than in areas with adequate health resources.

Recommendations

- Continued Federal funding is critical to support surveillance used to target areas for early cancer screening, cancer prevention, and cancer control efforts.

- Requests for Applications (RFAs) and other grant and contract mechanisms should provide set-asides or funding preferences for rural populations, including rural white populations; criteria for grants usually specify preferences only for minority populations.

MS. JACKIE SHAVER

Background

Ms. Shaver was diagnosed with breast cancer at age 27. At that time, she was unemployed and uninsured and was ineligible for medical assistance. Upon discovering a lump in her breast, she was referred to the Health Department, through which she was able to receive a free mammogram. Because of her age, the health providers required that the lump be palpable before they would allow her to have the mammogram, which showed either low-grade carcinoma or a cyst. When the cyst could not be aspirated, a biopsy was performed by Ms. Shaver's family physician. The tissue proved to be cancerous. She was referred to a surgeon, and mastectomy and axillary dissection were performed; all nodes were negative. Ms. Shaver was told that no further treatment was needed, but she insisted on seeing an oncologist, who recommended and supervised six months of systemic therapy. Ms. Shaver has been cancer-free for seven years.

Witnessing in the Heartland (WITH) is a branch of the National Witness Project, a breast and cervical cancer education program aimed at increasing the number of African-American women who practice regular cancer screening through BSE, mammography, CBE, pelvic examinations, and Pap tests. The Witness Project conducts outreach in the community through church groups, community organizations, beauty salons, and health fairs. A panel of African-American women shares its triumph over cancer, the message that cancer is not an automatic death sentence, and the importance of catching and treating cancer at its earliest stages. In addition to offering hope, the program teaches women BSE and other things they can do to help protect themselves, provides question-and-answer sessions, helps women find resources for free or low-cost services, and assists in making appointments.

Key Points

- Men or women who suspect they may have cancer, even if they are relatively young, need to be assertive about seeking a sonogram, biopsy, or other appropriate diagnostic testing rather than agreeing to "watch and wait." Physicians should be more suspicious of symptoms in younger patients.
- General and family physicians are not informing patients about the possibility of participating in clinical trials and are not providing adequate information about treatments of all types and their side effects.
- The number of cancer patients between 30 and 50 years of age appears to be increasing. Many physicians are not teaching BSE, conducting CBE adequately, or providing correct information about when to obtain mammograms.
- Funds to pay for cancer treatment are needed for women who receive free screening and in whom an abnormality is detected. Those with insurance are facing significant difficulties in getting their HMO or other insurer to pay for diagnostic testing and treatment.

MS. PEGGY JOHNSON

Background

In 1989, Ms. Johnson helped bring the Komen Foundation Race for the Cure to Wichita, Kansas. With the proceeds of that event, the first free mammography program in the county was established, providing 375 screenings to underserved women in its first year. The program was later expanded statewide. In 1996, Kansas received funding through the CDC Breast and Cervical Cancer Screening Program. This funding enabled the Komen-funded program to provide screening to women not eligible for the CDC program (i.e., those under age 50), as well as education and outreach grants to other State organizations. The CDC-funded services continue to improve and grow.

Key Points

- Last year, Kansas began participating in the Komen Clinical Research Affiliates Funding Trials (CRAFT) program to encourage greater participation in clinical trials by both patients and physicians. To participate in the pilot programs, affiliates were required to first conduct a community assessment to determine local gaps in participation or support. The Kansas survey revealed a considerable lack of understanding of clinical trials among survivors, doctors, and community volunteers. Despite concerns about being “guinea pigs,” patients indicated that they would have considered a trial had their doctor suggested it. A greater lack of knowledge and willingness to participate was found among minority women questioned. Surgeons surveyed felt it was not their role to recommend trials, and oncologists expressed little or no knowledge about trials and how they worked. There appeared to be little enthusiasm in the medical community for promoting clinical trials and translating the latest research into viable treatment options for patients.
- The Wichita Community Clinical Oncology Program (CCOP) is one of the highest accruing CCOPs in the Nation, but as little as 50 miles outside of the city, there is little or no participation in trials. Minority accrual is an issue. To help address this issue, a CRAFT grant has been awarded to hire a clinical outreach nurse to provide education and awareness programs in the minority communities of central Kansas and help promote participation of minority women in clinical trials.
- A second CRAFT grant has been awarded to a small regional cancer center for a staff position to help match newly diagnosed breast cancer patients to appropriate clinical trials. Information about the trial will be sent to the patient’s physician along with the pathology report. In addition, a vigorous education campaign for physicians has been initiated to help eliminate a barrier identified in the community assessment—specifically, that referring physicians had little or no training in clinical research.
- The Wichita Medical Research Institute is considering the possibility of sponsoring a workshop to educate and familiarize physicians and their staffs with the world of research and clinical trials. Funding for such a workshop is being pursued.
- The Government and the medical schools have the best opportunities to change physician attitudes toward research and clinical trials.
- The recent Executive Order mandating coverage for clinical trials for Medicare beneficiaries is an important step, but similar action is needed to provide coverage for those insured in the private sector.

Recommendations

- It is important that government find ways to improve physician participation in clinical trials and to disseminate research results to physicians to enable them to provide better care to patients. This is especially important in rural areas.
- To encourage increased physician participation in clinical trials, adequate funding is needed for protected research time and for support personnel such as data managers, clinical research nurses, and outreach workers.

MS. CLAUDIA WOJDYLAK

Background

Ms. Wojdylak works in Garden City, Kansas, population 27,000, located approximately 230 miles from Wichita. As an outreach nurse for the Kansas Breast and Cervical Cancer Free to Know program, she works with women under age 65 whose income is at or below 200 percent of the poverty level. Most are uninsured or underinsured minority women who are primarily Hispanic or Asian. The program especially targets women who have never or rarely been screened.

The program is funded not only by CDC, but also through a variety of partnerships with national and local advocacy and service organizations. Grants from these organizations have enabled the program to hire bilingual lay health care workers to help reach the Hispanic population. A newly formed, volunteer Hispanic women's coalition provides translation, education, transportation, and other services to the community.

The program is housed in the United Methodist Mexican American Ministries Community Health Center in a residential neighborhood, enabling people to walk to the Center. The Center provides a clothing center, a food pantry, and help with immigration papers in addition to health services. The program also shares space with a police mini-station in a trailer park where many of the Asian population reside. Saturday clinics enable people to walk in for screening and annual examinations.

Key Points

- The program faces difficult challenges in finding ways to help clients pay for followup care when an abnormality is detected. Providers do not offer discounted fees to the uninsured and may require half of the fee prior to the procedure. For poor clients, this is an insurmountable barrier to treatment. The program has used its various grant funds to pay for followup care for patients. Many providers will not accept the Free to Know program reimbursement for screening.
- Ms. Wojdylak recounted the experience of a 53-year-old patient with an abnormal CBE who was referred for a surgical consultation and scheduled for a biopsy. She lived 25 miles outside of town and had no transportation, no phone, and no family. Her appointment was arranged by mail, and she got a ride to town in order to spend the night at a homeless shelter prior to her surgery. After walking to the surgery center, she was turned away because she did not have \$500 in cash; the center wanted half of the \$1,000 charge that day. Since she did not have it, she was turned away. The patient walked back to the homeless shelter and called Ms. Wojdylak, who interceded with the surgery center and used program funds to pay for the biopsy, which was negative.
- Another barrier to better care is system capacity. As a result of outreach and education, community women become more aware of the need for screening and enthusiastic about

being screened; when they call for an appointment, however, they are told the wait is several months. Waiting times are long even for women who have symptoms.

- There is a particular lack of resources for women aged 40 and younger, who cannot be funded through the CDC program. Ms. Wojdylak cited the case of a 39-year-old woman whose breast lump was detected by CBE four years ago. She was advised to get a mammogram, but did not because she could not pay for it. The following year, the lump remained, but again the patient did not get the mammogram because of cost. A year later, the woman read in the newspaper about the Program's Komen Foundation funding and called for a mammogram appointment. Since then, she has had a mastectomy, chemotherapy, and radiation and now owes \$70,000. Her followup care at the local for-profit clinic costs \$125 monthly; if she does not stay current with these charges, she will be refused further care. Despite applications to various local programs and charitable organizations, she has to date been unable to secure additional assistance.
- Ms. Wojdylak sees the greatest needs in her community as: funding for screening mammograms for women under age 50, treatment for women who do not qualify for charitable program assistance, and more providers who will care for the underserved population.

DR. CLAUDIA PEREZ-TAMAYO

Key Points

- Rurality is a condition common to some part of every State in the country and is itself a source of disparities in health care. One of every four Americans lives in a rural area. Kansas is among the most rural of States. Like many Midwestern States, Kansas has only a single university that—in contrast to Michigan, which has several universities and medical schools distributed throughout the State—cannot offer much help in providing care for the underserved.
- In many rural communities, there is no public transportation, and there is a larger aging population than in urban areas. Some areas are so remote that there is no radio or TV reception. In addition, the agricultural lifestyle comprises a distinct culture. Uninsured status is 20 percent higher in rural communities because so many are self-employed or seasonal workers.
- In rural communities, care must be provided locally. Dr. Perez-Tamayo has sought to build a network of radiation facilities to improve access for patients. These facilities are barely self-sustaining. The program provides free transportation and lodging for those who need it. Arrangements for free care have been established with some local hospitals.
- Regardless of ethnic/racial/cultural group, all poorer people with cancer share the problems of having a life-threatening illness, of being weakened, and, usually, of being elderly. In Kansas, these issues are compounded by rural residence, lack of transportation, language differences, and fixed incomes among the elderly. Frequently, oncologists evaluating such patients do not even consider them for protocols because of these barriers, and the patients typically do not know what treatment options exist for their cancers.
- The American College of Radiology (ACR) has recognized the special issues of rural communities and has established the Small and Rural Practice Commission to help get information and services into the rural community.

- In many rural communities, cancer care is provided by itinerant oncologists; many may visit a community only once; thus, lack of patient trust is a serious barrier to effective care.
- National carve-out operations providing oncology care are not effective in rural areas, and the federally funded community oncology programs are so underfunded that they, too, are marginally effective.
- It is exceedingly difficult to attract oncologists to rural Kansas, since reimbursements are low and grant monies are limited because the rural population generally does not fit the grant eligibility criteria.
- To participate in clinical trials in Kansas, an oncology professional must belong to the Wichita Community Clinical Oncology Program or the Cooperative Group Outreach Program. Rural physicians have been excluded from these organizations due to funding issues. Many of the rural oncologists in the State, whose numbers includes some minority individuals, are well trained and board-certified and would welcome an opportunity to bring state-of-the-art care to their patient populations.

Recommendations

- To achieve effective cancer control among the underserved, a State advisory board or State task force is needed that works at the local level. Rural communities do not fit the urban care paradigm; policies that are “one size fits all” do not work. Rural issues must be addressed to bring discovery to the local community.

DISCUSSION—STATE OF KANSAS

Key Points

- The Breast and Cervical Cancer Screening Program staff receives many inquiries concerning other cancers. In Kansas, an adult learning center serving the southwest part of the State is used as a forum for cancer education.
- Clinical trials research is not valued as highly as individual research by university faculties or prestigious professional societies, which confer promotions and status on those who publish either individually or as the first author of a paper. This system of rewards discourages providers from participating in clinical research or choosing clinical research careers and thereby impedes progress against cancer.
- Those in a teaching setting have protected time for research, but practitioners in the local community are under ever-increasing pressure to produce income from patient care and cannot afford the time required to participate in research. Community institutions cannot provide support for protected research time to their providers or for research support staff. Community physicians will not be attracted to participate in research unless funding incentives can be provided.
- It also will be necessary to provide training and engender enthusiasm for clinical research and public health at the medical school level. For example, the Kansas University Medical Center recently has developed curricula to educate the next generation of physicians on the application of evidence-based medicine to individual patients and their patient community.
- In the CDC Breast and Cervical Cancer Screening Program nationally, ten percent of those with abnormal mammograms or CBEs do not receive necessary followup; this percentage is higher for abnormal Pap smears. It was noted that in Kansas and elsewhere, some of these women may fail to receive treatment, not because they have “fallen through the cracks,” but

because they have chosen not to pursue treatment as recommended. More caseworkers would help to retain both subgroups in the system to ensure that they are treated.

- In rural communities, research support staff are crucial to the physicians' willingness to offer clinical trials; because of the paperwork involved, many physicians choose not to offer research protocols if there will be no help with the documentation required.
- Surveillance data are important for defining disparities and trends, but data (or research) are not the answer to the immediate needs for care experienced by people all over the Nation. It also was pointed out that in many cases, funds to support actual health care are allocated based, not on the available data on areas of need, but on institutional or political preferences or misperceptions of need. The data are useful for showing where the real gaps are.

STATE OF ILLINOIS

Presenters:

Dr. Charles Bennett

Dr. James Wade

Ms. Linda Maricle

DR. CHARLES BENNETT

Key Points

- Prospective randomized clinical trials (RCTs) are necessary to determine the efficacy of new treatments, yet less than three percent of adult cancer patients participate in clinical trials.
- Barriers to enrollment in clinical trials include patient reluctance, financial burdens, and physician reluctance.
- It is difficult to obtain informed consent for clinical trials. This patient-related barrier to enrollment is due in part to the fact that informed consent documents are written at reading levels significantly above the literacy levels of many patients. In addition, the consent forms provide information that frightens many patients and causes them to refuse participation. Some patients also do not want to be randomized or receive a placebo, and the rigidity of many trial designs is discouraging to physicians and patients.
- Physician concerns relate to three areas: (1) the physician/patient relationship and the patients' expectations that the physician will understand the trial and make the best decision for the patient, (2) concern about inconvenience and financial burden, and (3) procedural difficulties and increased followup times. It has been estimated that some physicians lose as much as \$100,000 in income due to unreimbursed time spent participating in clinical trials—time spent on enrollment, data management, and the informed consent process. Despite these concerns, 78 percent of physicians surveyed by Dr. Bennett and colleagues indicated that they believe patients receive better care on clinical trials than through standard treatment.
- Health insurance often does not cover all clinical trial costs. Patients may decide not to enroll because of these financial burdens. Many insurers do not cover patient costs on clinical trials because they maintain that such care is more expensive than routine patient costs for standard treatment. A study conducted by Dr. Bennett and colleagues showed roughly equivalent costs for two sets of patients with advanced cancers: half of whom were on trials and half of whom received standard care. These findings are consistent with those of other similar studies.

Clinical trials have become more efficient; they no longer call for many of the extra tests required in the past.

- It is important that private insurers cover patient costs under clinical trials, as has recently been mandated for Medicare patients by Executive Order.
- Physicians may hesitate to adopt new treatment procedures even after they have been proven effective.
- Barriers to implementation include those associated with low literacy, such as difficulty reading patient education materials, understanding physician instructions, and the inability to adequately understand consent forms. One study showed that African-American men with prostate cancer presented with later-stage disease and had lower literacy levels than white men; however, when data were adjusted for literacy, age, and city of residence, race was no longer a significant predictor of late-stage presentation. The investigators concluded that low literacy may be an overlooked barrier to participation in health care and new treatments.

Recommendations

- There is a need for coverage for orally administered anti-cancer drugs.
- The system of reporting adverse reactions to cancer care drugs should be expanded beyond the reporting system used for clinical trials to include all patients regardless of the type of care administered or the treatment setting.

DR. JAMES WADE

Background

Illinois is a diverse Midwestern State with a population of about 12.2 million. About two-thirds of the population live in the Chicago metropolitan area; another three million live in other large cities throughout the State, and about a million live in rural areas, including Appalachia.

Illinois has two NCI-designated Comprehensive Cancer Centers, four Community Clinical Oncology Programs (CCOPs), one minority-based CCOP, and multiple clinical trials networks affiliated with various universities. Virtually every medical oncologist in the State has ready access to participate in peer reviewed, high-quality, NCI-sponsored clinical trials.

In addition, the Illinois Department of Public Health is highly active. Cancer is a reportable disease in Illinois. Residents can elect to apply part of their income taxes to cancer research projects across the research spectrum—from basic to applied research. Moreover, Illinois is the home State of several of the Nation's largest patient advocacy organizations.

Each year, 58,000 to 60,000 new cancer cases are diagnosed in Illinois; of these, approximately three percent participate in clinical trials, most in Phase II and III trials. Most are on NCI-sponsored trials, with far fewer participating in industry-sponsored or Food and Drug Administration trials.

Key Points

- The Kater/Hagen/Howe report describes breast cancer treatment in rural Illinois hospitals compared with hospitals in urban centers of the State. The study compared mastectomy versus lumpectomy rates, the percentage of women receiving radiation after lumpectomy, the percentage of women with Stage II disease who also receive adjuvant treatment, and the percentage of women receiving a mammogram of the contralateral breast upon a diagnosis of

breast cancer. Overall, small or rural hospitals, especially those without medical oncology consultants, performed worse than did those with available medical oncology consultations. The availability of this expertise to primary care physicians seemed to facilitate the diffusion of knowledge into primary care for women.

- CCOPs are an excellent model for implementing discoveries at the bedside. Studies have shown that CCOPs are an effective vector for new knowledge in community practice. In addition, it has been shown that patients participating in CCOP trials received care equivalent to those treated at university cancer centers. Thus, while the CCOP is an effective mechanism for bringing the benefits of research to the public, reimbursements to physicians fall far short of the effort involved and pose a significant barrier to progress in this area.
- Most providers in the State consider NCI-sponsored trials to be of the highest quality (compared with FDA or industry-sponsored trials).
- Populations in Illinois that tend to get less than optimal care include isolated communities such as those in the inner cities, the uninsured and underinsured on the south side of Chicago, the rapidly growing Asian and Latino populations, and rural residents, including the Amish. Amish women virtually always present with later-stage breast cancer. They are not educated beyond the eighth grade and are not afforded preventive health services. Reaching out to these isolated communities has been very difficult. Major cultural barriers exist that are not well understood.
- Measurement of treatment type, appropriateness, or outcomes is inadequate in Illinois. Reimbursement is inadequate for care provided to vulnerable populations, whether uninsured, underinsured, or covered by Medicaid. Each year, a Race for the Cure raises approximately \$80,000, which is used to pay for free screening for underserved women in central Illinois. Yet the screening program remains underutilized; each year there are funds left over—even after payment for mammograms, physician consultations, and biopsies. Fear keeps many people from taking advantage of these services.
- The new Medicare APC hospital reimbursement scheme for outpatient services will threaten a fragile financial balance. Medicare reimbursements for office-based therapy and radiation therapy already are inadequate. The 1998 Wiseman/Beard report indicates that, based on care and work measurements derived from Health Care Financing Administration data, oncologists are underpaid \$275 million per year for chemotherapy administration in the office setting. In addition, current reimbursement for nursing, teaching, clinical research, oncology social work, and tumor registry staff is inadequate and will get worse under the proposed reimbursement changes. Reductions in Medicaid reimbursements also are pending. These reductions will have a series of downstream effects that will increase the distance from state-of-the-art care to its implementation for all people.
- In recent years, the physician's role has changed from being a provider of information to being an interpreter of information. Patients need help to evaluate and prioritize information they access from various sources. Helping patients obtain information on what constitutes outstanding cancer care takes many forms, such as public service announcements, advertisements, additions to grade school or high school curricula, or Web-based information.

Recommendations

- The era has ended in which oncologists have been able to make up through drug costs the shortfall in reimbursement for chemotherapy administration. Eliminating the margin for chemotherapy drugs may be appropriate, but then adequate coverage for the cost of their administration must be provided.

- Community clinical research participation should continue to be encouraged. The number of CCOPs should be increased such that every community and every oncologist could participate.
- Research requirements should be simplified, including simplifying informed consent templates and eligibility and pretesting requirements.
- Greater efforts should be made to encourage the participation of underserved populations in clinical trials. Minority-based CCOPs are a step in this direction, but other mechanisms should be piloted, and those that are effective should be supported.
- Greater public awareness is needed of clinical trials as an indicator of quality care.
- More research is needed on how best to deliver cancer care to all populations. More measurements of performance and quality, such as patterns-of-care studies, should be conducted.
- Better decision analysis is needed. The IOM report indicated that the most critical decisions are those made shortly after a patient's diagnosis. We need to better understand how and by whom these decisions are made, and how they can be optimized. One option is to establish a tumor board at every hospital so that all cancer cases are reviewed prospectively.
- Better outcome analysis is needed; it remains unclear how best to measure survival and quality of life.
- A national manpower plan for oncology professionals of all types should be developed. We are facing an enormous personnel shortage in all areas of oncology care. In particular, there is a need to train a new cadre of oncology nurses; the average age of oncology nurses in practice is 40 to 45 years, and the number of people entering the field is shrinking. These professionals are crucial to patient and family communication in cancer care.

MS. LINDA MARICLE

Background

The Susan G. Komen Breast Cancer Foundation was established in 1982 by Nancy Brinker, in memory of her sister who died of breast cancer in 1980 at the age of 36. Today, the Komen Foundation is an international organization, a network of volunteers working through 114 local affiliates to eradicate breast cancer as a life-threatening disease. Since its inception, the Foundation has raised more than \$214 million to support breast cancer research, education, screening, and treatment. The Foundation also awards dissertation grants and postdoctoral fellowships to recruit young scientists to the field of breast cancer research. At the Peoria affiliate, as at others, 75 percent of funds raised stay in the local area to fund local programs and services.

Foundation communication tools include a website, a quarterly newsletter, and a research newsletter. These sources provide easily understood information designed for distribution to the grassroots affiliate network.

In the year 2000, 8,900 Illinois women will be diagnosed with breast cancer, and 2,000 women will die from the disease. Illinois' breast cancer mortality rate from 1992-1996 is higher than the national average.

Key Points

- We have known for 15 years that breast conservation surgery followed by radiation therapy is as effective as mastectomy for certain breast cancers. Yet, recent studies continue to show that otherwise eligible women continue to receive mastectomy based upon the type of insurance they have, social class, education, place of residence, and type of referral received. We still have far to go to ensure equal access and end disparities in breast cancer care.
- To promote links between patients, researchers, physicians, and advocates, the Komen Foundation requires that those receiving its funding, regardless of the research area, present the results and implications of their work to foundation affiliates at Komen's national conferences. In addition, Komen sponsors the Survivors/Scientists Program at the annual meeting of the American Association of Cancer Research to promote information exchange between the two groups.
- The Illinois income tax check-off initiative raised \$325,000 last year for new cancer research initiatives within the State; no other State has such a program.
- The Komen Foundation operates a toll-free breast care help line answered by trained volunteers; in 1999, the help line received more than 90,000 calls. The information provided encourages patient self-advocacy and empowerment. Other State-level programs include local-level grants for research and the development of community-based programs; special license plates, part of the fees for which are used to provide services to medically underserved women; and the Komen Race for the Cure (one of 107 5-kilometer runs held nationwide and in two foreign countries). The Komen Race for the Cure creates community awareness of breast cancer and the importance of regular screening and provides hope for surviving the disease.
- To ensure that local programming responds to local needs, each affiliate is required to develop a community profile that highlights gaps in breast health services and the groups that may be underserved. Underserved populations may be those facing barriers to screening, education, or treatment as a result of poverty, ethnicity, culture, mental or physical state, housing status, geographic location, literacy/language difficulties, sexual orientation, age, lack of education, or lack of adequate health insurance.

Recommendations

- We must educate consumers about research efforts and appropriate care. It is incumbent upon researchers, especially those funded with public dollars, to translate their findings into lay language that all can understand.
- Local, flexible customization of funding for research or service projects is key to their success. To accomplish this, we must understand who is underserved and their barriers to care. The needs and interests of people in local communities should define local funding priorities.
- We must continue to work to ensure expeditious approval of and patient access to important new cancer therapies. All patients, including the elderly, must have equal access to such therapies.

DISCUSSION—STATE OF ILLINOIS

Key Points

- It was suggested that to improve clinical trials availability and participation, all of the Cooperative Groups could be organized under a single mechanism. Information on trials

would be available on the Internet. Incentives would be provided for oncologists and patients to encourage participation in trials. Public and private payers would need to cover care provided to trials participants without question. It was noted that following recommendations of a group convened by NCI and chaired by Dr. James Armitage to evaluate the NCI clinical trials system, implementation plans embracing many of these ideas are being drawn up that would, in essence, make every oncologist's office a potential clinical research site. A pilot project is underway based on these ideas. Another pilot study will begin in summer 2000 to try to centralize institutional review board (IRB) and certain other clinical trials-related functions.

- However, it was noted that these plans to improve the clinical trials system will fail if the current trend in reimbursements to participating physicians cannot be reversed. In addition, oncology careers need to be made more rewarding in order to attract the best talent to the field; at this time, many residents graduate with no positions open to them or choose not to go into medical oncology because of its shrinking rewards. For ten years, ASCO has tried without success to persuade the American Medical Association and HCFA that providing oncology care is complex, requiring additional overhead and nursing that should be reimbursed.

CLOSING REMARKS—DR. HAROLD FREEMAN

Dr. Freeman highlighted the day's presentations and reiterated the Panel's purpose in this series of meetings—to explore and document the current disassociation between the research and delivery enterprises in providing the best possible cancer care to all. The Panel's findings will be presented in a report to the President of the United States in approximately 18 months.

I certify that this summary of the President's Cancer Panel meeting, *Improving Cancer Care For All: Applying Research Results, Ensuring Access, Ending Disparities*, held on June 15-16, 2000, is accurate and complete.

Certified by: _____ Date: _____

Harold P. Freeman, M.D.
Chair
President's Cancer Panel