

MEETING SUMMARY PRESIDENT'S CANCER PANEL

IMPROVING CANCER CARE FOR ALL: REAL PEOPLE—REAL PROBLEMS WHY DON'T ALL AMERICANS GET THE BEST AVAILABLE CANCER CARE?

February 1-2, 2001
Los Angeles, California

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 fifth in a series of seven regional meetings to explore issues that affect the ability of communities to provide cancer care—including prevention, education/communication, detection, treatment, diagnosis, rehabilitation, palliation, and end-of-life care—to people in the diverse neighborhoods of the Nation. This meeting brought together representatives from six States in the northwest/western regions and the Pacific Territories to discuss these issues, the barriers faced at local levels, and local- and State-level efforts to address them. The State delegations 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
Dennis J. Slamon, M.D.

National Cancer Institute

Maureen O. Wilson, Ph.D., Assistant Director, NCI, and Executive Secretary, President's Cancer Panel
Jon Kerner, Ph.D., Assistant Director, Research Dissemination and Diffusion, Behavioral Research Program, Division of Cancer Control and Population Sciences

Speakers

Norma Ada, M.D., Internist/Pediatrician, Commonwealth Health Center (Pacific Territories)
Aloiamoa Anesi, M.S.CuB., Chief of Internal Medicine, Lyndon Baines Johnson Tropical Medical Center (Pacific Territories)
Steven Asch, M.D., M.P.H., West Los Angeles Veterans Administration Medical Center, RAND Corporation (California)
Donald Austin, M.D., M.P.H., Professor, Department of Public Health and Preventive Medicine, Oregon Health Sciences University (Oregon)
Betty Byrtus, Coordinator, Curry Breast Health Network, Curry General Hospital (Oregon)
Lourie Campos, M.P.A., Policy Analyst, Community Health Partnership (California)
Peggy Carey, B.S.N., M.P.A., Cancer Research Director, St. Charles Medical Center (Oregon)
Clayton Chong, M.D., Medical Oncologist (Hawaii)
Frank A. Chong, M.S.W., M.Div., Executive Director, Waikiki Health Center (Hawaii)
Theresa Damian, Community Representative (Alaska)
Darlene deManincor, Ph.D., Support Group Facilitator, Women's Cancer Resource Center (California)

Gwendolyn Favila-Penney, B.S., L.V.N., Director, Cancer Navigator Program (California)

Anne M. Gore, M.P.H., Program Director, Breast and Cervical Health Check, Section of Maternal, Child, and Family Health (Alaska)

Mary E. Guinan, M.D., Ph.D., State Health Officer, Nevada State Health Division (Nevada)

Robert L. Haddock, D.V.M., M.P.H., Territorial Epidemiologist/Cancer Registrar, Guam Department of Public Health and Social Services (Pacific Territories)

Marcia Hastings, Director of Women's Health, YWCA of Anchorage, ENCORE^{plus}® Program (Alaska)

Paula B. Henry, Community Representative (Alaska)

Linda Jackson, M.S., R.N., C.H.E.S., Health Promotion Specialist, Health Education/Health Promotion Division, Spokane Regional Health District (Washington)

Sandra Jackson, President, Courage Unlimited (Nevada)

Betty Johanna, Community Representative (Washington)

Nathalie M. Johnson, M.D., F.A.C.S., Medical Director, Legacy Cancer Services (Oregon)

Peter Jones, Ph.D., D.Sc., Director, University of Southern California Norris Comprehensive Cancer Center (California)

Pama Joyner, Program Director, Breast and Cervical Health Program, Washington State Department of Health (Washington)

Marjorie Kagawa-Singer, Ph.D., R.N., M.N., Assistant Professor, University of California at Los Angeles (UCLA) School of Public Health and Asian American Studies (California)

Mary Kailukiak, Community Representative (Alaska)

Colette Kalawe, Community Representative (Hawaii)

Elaine Low, Executive Director, Guam Unit of the American Cancer Society (Pacific Territories)

Thien-Nhien Luong, M.P.H., Health Program Manager/Senior Epidemiologist, County of Santa Clara Public Health Department, Central Planning and Evaluation Division, Data Management and Statistics (California)

Donald O. Lyman, M.D., Chief, Division of Chronic Disease & Injury Control, Prevention Services Program, California Department of Health Services (California)

Jennifer Malin, M.D., UCLA Department of Medicine, RAND Corporation (California)

Gregory G. Marino, D.O., F.A.C.P., Head, Department of Hematology-Oncology, Alaska Native Medical Center (Alaska)

Lawrence Matheis, Executive Director, Nevada State Medical Association (Nevada)

Corliss McKeever, M.S.W., President/CEO, African American Health Coalition (Oregon)

Shirley McKenzie, R.N., O.C.N., Manager, The Breast Program, Alta Bates Comprehensive Breast Center (California)

Leona Miller, Community Representative (Washington)

Lauri Ogumoro, M.S.W., Commonwealth Health Center (Pacific Territories)

Neal Palafox, M.D., M.P.H., Interim Chair and Director, Department of Family Practice and Community Health, John A. Burns School of Medicine, University of Hawaii (Pacific Territories)

Maria Parra, Community Representative (Nevada)

Joe Jay Pinkham, Community Representative (Washington)

Virginia Pressler, M.D., M.B.A., Deputy Director, Health Resources Administration, Hawaii State Department of Health (Hawaii)

Joan Ramos, M.S.W., Resource Coordinator, The Max Foundation (Washington)

Ken Retterath, Director, Adult Services for Washoe County Department of Social Services (Nevada)

Terrie Restivo, Community Representative (California)

Kathlyn Tuakalau, Community Representative (Hawaii)

Ron Zeno, Community Representative (California)

FEBRUARY 1, 2001

OPENING REMARKS—DR. HAROLD FREEMAN, CHAIRMAN

In opening the meeting, Dr. Freeman noted:

- This series of seven regional public meetings grew out of efforts by the President's Cancer Panel in 1999 to evaluate the National Cancer Program. During that year, a significant disconnect was identified between research discoveries and delivery to the public of the benefits of these discoveries. The Panel concluded that the unequal burden of cancer on the poor, ethnic minorities, and the underserved must be relieved.
- Regional meetings have already been held in Omaha, Nebraska; Burlington, Vermont; Billings, Montana; and Nashville, Tennessee. After this meeting in Los Angeles, two additional regional meetings will be held—in Albuquerque, New Mexico, and Washington, DC. The process will culminate in the President's Cancer Panel's Report to the President of the United States at the end of 2001.
- Today's meeting features speakers from the States of California, Alaska, Oregon, Nevada, and Hawaii, as well as the Pacific Territories and the State of Washington. This 2-day meeting will also include an opportunity for the public to present questions and comments to the Panel at an evening Town Meeting.

**WELCOME—DR. PETER JONES, DIRECTOR, NORRIS COMPREHENSIVE
CANCER CENTER**

In welcoming meeting participants, Dr. Jones remarked that:

- The Norris Comprehensive Cancer Center at the University of Southern California (USC) is one of the oldest NCI-designated Comprehensive Cancer Centers (CCCs), having held that designation since 1973. Cancer research is one of the top priorities at the USC School of Medicine. The Cancer Center is one of three CCCs located in the most ethnically diverse counties in the United States. It is one of 10 CCCs in the Nation with its own cancer hospital, in addition to clinical facilities at the county hospital and a pediatric facility at the Children's Hospital, Los Angeles.
- Population-based resources, which rely on the region's ethnic diversity and include a Surveillance, Epidemiology, and End Results (SEER) program registry, drive the Cancer Control and Molecular Epidemiology programs.
- Members of the Norris Comprehensive Cancer Center have over \$85 million per year in peer-reviewed grant support from the Federal Government and other organizations, and an additional \$27 million in research support from the National Cancer Institute (NCI).
- Achievements of the Norris Comprehensive Cancer Center include discovery of the *Jun* oncogene, discovery of the link between steroid hormones and breast and prostate cancers, development of new techniques for treating bladder cancer, establishment of relationships between DNA manipulation and cancer, and development of molecular markers for neuroblastoma in children and for bladder cancer. Major inroads have been made into molecular epidemiology.
- A major strength of the Cancer Center is its capacity to translate epidemiologic findings into cancer control and prevention programs—for example, in large programs such as smoking control and through pioneering studies on behavioral and hormonal modification.

DIRECTOR'S REPORT—DR. JON KERNER, ASSISTANT DIRECTOR, RESEARCH DISSEMINATION AND DIFFUSION, BEHAVIORAL RESEARCH PROGRAM, DIVISION OF CANCER CONTROL AND POPULATION SCIENCES, NATIONAL CANCER INSTITUTE

Representing Dr. Richard Klausner, Director, NCI, Dr. Kerner welcomed the participants.

Key Points

- The Fiscal 2001 budget, approved in December 2000, included a 13.6 percent increase over the amount awarded to the NCI in Fiscal Year 2000. In Fiscal Year 2000, the NCI spent more than \$3.3 billion, the overwhelming majority of which supported more than 4,500 extramural research grants, the largest number of research grants supported in NCI's history.
- In Fiscal Year 2000, more than 1,400 research grants were awarded to the six States represented at this meeting, totaling almost \$500 million. California received the largest amount of money and the most grants, followed by Washington, Oregon, Hawaii, Nevada, and Alaska.
- Dr. Klausner is committed to continuing the trend of increased investment in cutting-edge science that will help achieve NCI's fundamental goal to develop interventions that reduce the incidence, morbidity, and mortality from cancer for all Americans.
- During the last 10 years, the rate of new cancer cases has declined an average of 1.3 percent per year from 1992 to 1997. The cancer death rate decreased 0.6 percent per year from 1991 to 1995; this decrease then accelerated to a rate of 1.7 percent per year from 1995 to 1997. Despite this progress, cancer remains a major public health burden—one that continues to be borne unequally by a number of population groups in the United States, particularly the poor and underserved.
- Dr. Klausner created a new NCI investment initiative to reduce cancer-related health disparities. The centerpiece of NCI's initiative is the newly created Center to Reduce Cancer Health Disparities, which will be located within the Office of the Director and will be headed by Dr. Freeman. The Center will not only focus on special populations research from a socioeconomic and cultural perspective, but also will include a health policy component to take the knowledge gained from research and translate it into new policy initiatives benefiting those who bear the greatest cancer burden.
- NCI will invest in new resources for: conducting fundamental and intervention research, increasing its capacity to monitor emerging cancer trends, expanding its health disparity training programs, and launching a new effort in dissemination and diffusion to help close the gap between discovery and delivery.
- NCI's new dissemination and diffusion program, Translating Research into Improved Outcomes (TRIO), has three components: database decisionmaking, adoption of evidence-based interactions, and partnerships to overcome infrastructure barriers at State and local levels.
- Data from the 2000 census and the Health Resources Services Administration (HRSA) indicate that of the approximately 48 million people living in the 6 States testifying at this meeting, more than 9 million (about 19 percent) lack health insurance. The percentage of uninsured ranges from a low of 10 percent in Hawaii and Washington to highs of 22 percent in California and 23 percent in Nevada.
- The second part of TRIO involves promoting the adoption of evidence-based interventions and ensuring their dissemination to those who need assistance. NCI is working with the Centers for Disease Control and Prevention (CDC), the Agency for Healthcare Research and Quality (AHRQ),

and the American Cancer Society (ACS) to format research evidence so as to be useful to clinicians. Intervention research products produced by NCI's R01 investigators will be available to all programs and communities via the Web.

- The third part of TRIO will use local cancer data and behavioral risk factor data to motivate action at the local level. Special partnerships will be developed to identify local and regional infrastructure barriers. NCI is working in special partnership with the ACS and the CDC to develop a series of training institutes called Comprehensive Cancer Control Leadership Institutes. The West Coast Institute is scheduled to open in Fiscal 2002.

STATE OF CALIFORNIA—PANEL I

Presenters

Dr. Donald Lyman

Ms. Terrie Restivo

Dr. Darlene deManincor

Ms. Shirley McKenzie

DR. DONALD LYMAN

Background

California's population differs from that of the rest of the Nation, with a minority (49 percent) described as non-Hispanic white as of the 2000 census. Thirty-one percent of California's population is Hispanic; 12 percent is Asian/Pacific Islander; 7 percent is African-American; and 1 percent is American Indian.

Key Points

- Although California's overall cancer rates are similar to those in the rest of the Nation, the incidence of and mortality rates from colon and rectal, lung, female breast, and prostate cancers in California are lower than the rates in the whole of the United States.
- In the 10 years since the 1989 initiation of the California Tobacco Control Program, the State's per capita adult cigarette consumption declined by 57 percent—twice as much as in the rest of the United States. Reduction has occurred across the four major ethnic groups.
- Estimated savings in smoking-attributable direct and indirect costs in California have reached more than \$8 billion. These substantial reductions reflect decreases in the frequency of and the mortality rate from tobacco-related cancers.
- Barriers to improved cancer care include culture, race, ethnicity, and language. Other barriers relate to access to care. California has a large proportion of uninsured individuals, inefficient technology transfer from bench to bedside, and uneven quality control standards.
- California's long history of leadership in cancer prevention and detection includes the Cancer Prevention and Nutrition Section, the Nation's most extensive and intensive diet and cancer prevention program related to the high-fiber, low-fat diet. Also included is the Cancer Detection Section, tied to both a Federal and a State-only program, that offers early cancer detection and treatment programs for high-risk populations. Current emphases in the detection program are breast, cervical, and prostate cancers, with colorectal cancer to be added in the future. Two other programs are the Cancer Research Section, which includes applied, laboratory, and clinical research; and the Cancer Surveillance Section, the largest population-based cancer registry in the Nation.

- Prevention is the most cost-beneficial—and the least utilized—intervention. Because it is the least expensive of all cancer-related scenarios, investment in prevention is worthwhile.
- Cancer prevention and control is not merely a medical issue, an economic issue, or an issue of demographics; it is an issue of social justice.
- The ACS 2015 goal of a 50 percent reduction in cancer mortality rates and a 25 percent reduction in cancer incidence rates is not overly optimistic; California intends to achieve that goal.

MS. TERRIE RESTIVO

Background

Ms. Restivo, who is with Native American Cancer Research, is the Southern California Coordinator for the Native American Cancer Survivor Support Circles. She is a 24-year cervical cancer survivor with a family history of breast cancer.

The 2000 Census counted 175,000 Native Americans in San Diego, Orange, Riverside, and Ventura Counties; Los Angeles was not included in this count. The Native American population in California is as large as the Asian population.

Key Points

- Insufficient cancer information is a significant barrier for Native Americans. Culture-specific sensitivities can deter Native Americans from obtaining the cancer information they need: Native American teachings say that being aggressive and assertive is rude, but aggressiveness and assertiveness are necessary to obtain the most useful cancer information.
- Many Native Americans are uninsured or underinsured; as a result, they are not receiving full and appropriate care.
- Social barriers to cancer prevention and care within the Native American community include alcohol, tobacco, and drug problems; lack of exercise and good diet; and statistical misclassifications.
- Due to environmental pollutants, cancer in Indian country is more prevalent now—both across the Nation and in California. Toxic waste dumps have been activated on or near reservations. Pollutants from the Leviathan mine, run by the State of California, are being dumped into the Carson River on the California/Nevada border. Bacterial pollution along Huntington Beach may be creating cancers, although no statistics are currently available.

DR. DARLENE deMANINCOR

Background

For the past 7 years, Dr. deManincor has facilitated the Support Group for Lesbians with Cancer at the Women's Cancer Resource Center in Berkeley, California.

Key Points

- Lesbian invisibility in social and medical research has made adequate health care impossible for lesbians.

- Four major barriers prevent lesbians diagnosed with cancer from obtaining the best available care: barriers within medical institutions, barriers within the insurance industry, barriers in social support, and barriers in research.
- Homophobia within the medical profession affects medical support. Because of the assumption of heterosexuality, and because of discrimination and homophobia, lesbians frequently do not have a good working relationship with primary care physicians.
- A 1986 San Diego survey of 930 medical doctors found that 23 percent were severely homophobic; 30 percent indicated that they would not admit a lesbian or gay person to medical school; 40 percent would not refer clients to gay or lesbian physicians; and 40 percent said they were uncomfortable treating gay and lesbian patients.
- In 1994, the Gay and Lesbian Medical Association surveyed 711 [member] physicians across the country. Fifty percent said they had observed heterosexual colleagues denying care or providing substandard care to gay and lesbian patients, and 88 percent had heard physicians make disparaging comments about gay and lesbian patients.
- Studies indicate that between 62 and 72 percent of lesbians withhold sexual orientation information from their primary care physicians and frequently feel uncomfortable enough to forgo even basic screening. A recent study indicated that 45 percent of lesbians do not get regular gynecological exams, and an additional 25 percent get only sporadic exams, so that 70 percent of the lesbian population is not getting primary cancer screening. Consequently, lesbians are diagnosed at later stages and have more difficult treatments and, frequently, poorer prognoses.
- The second major barrier faced by lesbians is adequate insurance and disability coverage. Many of the 43 million uninsured Americans are women in marginalized jobs. Because of external and internal homophobia, many lesbians are in those marginalized jobs. As a result, when they are diagnosed with cancer, their options for treatment may be few due to limited insurance. They must return to work too early, or they are forced to choose between continuing to work during debilitating treatments and losing their jobs.
- Privacy issues are another significant concern. With increasing use of shared computer records, a lesbian who “comes out” to her doctor places herself at risk that that information in her medical records will be accessed by insurance companies and her workplace notified. To avoid compromising privacy—and for other reasons—many lesbians use complementary and alternative therapies.
- The importance of social support groups in recovery from cancer is well established. Because of widespread social disdain, however, many lesbians feel uncomfortable in traditional support groups; some support groups are unwelcoming or even hostile to women who identify themselves as lesbians. The lesbian community has minimal resources and depends on volunteers and local support for funding and for operating the few clinics and support groups that exist. Only 14 support groups for lesbians with cancer exist throughout the country. One of these is in the San Francisco Bay area, where the lesbian population is relatively large. Support from one’s partner also is important in recovery from cancer, but few if any support groups exist for partners of lesbians diagnosed with cancer.
- Little money has been spent for research on lesbian health. Much of the available literature suggests that lesbians are at higher risk for certain cancers; for example, their breast cancer risk is one in three, compared with one in seven for heterosexual women. Several risk factors—few pregnancies, higher body mass index, and higher levels of smoking and drinking—put lesbians at greater risk for colorectal, lung, and breast cancer.

Recommendations

- Lesbian-sensitive health care providers would make health care much more accessible to lesbians. For example, the Mauntner Project, along with the CDC and projects in Washington, DC, has designed a workshop to teach health care providers how to make culturally appropriate changes to eliminate some of these disparities. The women in Dr. deManincor's support group have suggested that this training be mandatory in medical schools.
- A number of early studies recruited study subjects from bars, the only places at which lesbians are known to congregate and where tobacco and alcohol use are the norm. More funding is needed for studies such as the current study at the Center for Lesbian Health Research at the University of California, San Francisco, and the study at the University of Chicago on postdiagnosis quality of life in lesbian cancer patients versus that of heterosexual patients.

MS. SHIRLEY McKENZIE

Background

Ms. McKenzie is the manager of the Breast Program at the Alta Bates Comprehensive Breast Center in Berkeley, California. The program, entitled Breast Health Access for Women With Disabilities, started in 1995 and developed as a partnership between the medical community and disability organizations. Breast Health Access for Women with Disabilities' goals are to: break down educational, logistical, and financial barriers; increase access to breast screening; develop alternative techniques and protocols; raise community awareness; heighten the sensitivity of the medical community to the needs of women with disabilities; and identify appropriate public policy issues that need further attention.

At the conclusion of her remarks, Ms. McKenzie showed a 2-minute videotape about the Breast Health Access for Women With Disabilities program.

Key Points

- Women with disabilities receive less cancer screening, and women with disabilities may be at higher risk for cancer, although this has not been studied definitively. Tumor registries do not collect data on disabilities.
- Seventeen percent of women have functional limitations: inability to walk or stand, spasticity or tremors, impaired coordination, impaired sensation, inability to reach, **(Note to speaker: please indicate what LEM stands for)** (LEM) abnormalities, visual impairment, cognitive impairment, lack of flexibility, and bowel or bladder incontinence. A 1996 survey of clients and providers identified some of the physical barriers to breast screening, including difficulty transferring to a standard exam table from a wheelchair, difficulty dressing or undressing, difficulty performing breast self-examination, and difficulty arranging appropriate transportation.
- Providers' attitudinal barriers also were described in the 1996 survey. Providers surveyed tended to focus on issues relating to the patients' disabilities and did not think about their patients' issues as women; as a result, Pap smears and breast exams often were deferred. Other provider attitudinal issues were: not knowing how to provide assistance, fear of injury to self or clients if the provider tried to lift them, reluctance to spend extra time in an already busy schedule, and lack of knowledge about specific disabilities.
- Clients' attitudinal barriers include preoccupation with other issues, lack of awareness of need, fear of being a burden, prior negative experiences with the medical community, reluctance to deal with accessibility issues, fear of bowel and bladder accidents, and a greater history of abuse than other populations.

- The Breast Health Access program includes the Mammocare method of instruction for breast self-examination; a 1 ½-hour private session that includes a clinical breast exam on an accessible table; teaching the woman about her breast tissue; and training spouses, partners, or attendants—tailored to each woman’s ability.

Recommendations

- More innovative ways to reach women with disabilities are needed. Outreach is needed for older women, and new technology is necessary to enhance older women's access to breast-health services, especially mammograms.
- Grant funding should be less fragmented.
- Greater cultural sensitivity is needed on the part of the medical establishment. All women and their needs should be respected. Medical professionals should work in partnership with women and must acknowledge women's mistrust of the medical model. Appropriate terminology should be used; for instance, "women with disabilities" should be used instead of "disabled women."

DISCUSSION—STATE OF CALIFORNIA—PANEL I

Key Points

- The major impediments to greater cancer control success in California include: lack of consistent techniques and funding for prevention activities such as screening, nutrition, and physical exercise; the body part-specific approach to outreach; funding for categorical outreach and medical care; and a need at the Federal level to look at prevention and treatment interventions in a more holistic, global way (e.g., the connection between cancer and the recent increase in Type II diabetes among obese children).
- California needs funding for interventions shown to be effective, technology transfer support, and additional demonstration projects.
- California has the largest Native American population in the Nation, and most of this population lives in urban areas, off the reservations. A statewide cancer registry addresses this fairly large population group; it is tied into NCI's SEER program, which also covers large Native American populations in New Mexico and elsewhere. Despite this useful database, these data for retrospective and prospective studies are not used optimally. Responsibility for the medical care, prevention, and followup of Native Americans differs depending on the State: Some States have total jurisdiction; some States share their responsibility with the Federal Government; and in some States, the responsibility rests entirely with the Federal Government.
- California faces a significant challenge in communicating prevention and other health messages to its diverse population. Sixty percent of elementary school students in California live in a home where English is not the first language. Specific outreach messages are attempted, where possible, with the large Spanish-speaking and Asian populations, but the nuances of specific dialects are challenging.
- California's significant population of undocumented aliens presents other challenges. Those who have obvious health problems are eligible for medical care immediately; for individuals who cannot demonstrate immediate need, alternate funding sources are available in the form of local partnerships that may include a local foundation, a county, and/or Medicaid. In a study being conducted by Ms. McKenzie's organization on women who were diagnosed with breast cancer and subsequently returned to work, 25 percent are illegal aliens. Many of them have gone without treatment.

Recommendations

- The Federal Government can facilitate implementation of preventive interventions and motivate local action to support their application in the community. California needs funding and technology transfer support for interventions that have been demonstrated to work; demonstration projects also

are needed. Key needs for which Federal support is needed nationwide—especially in smaller States— are leadership, information transfer, staffing, and funding.

- Ethnic classification of Native Americans should be standardized so that the Native American community and the medical/health community have reliable statistics about the extent of cancer in Native American populations.

STATE OF CALIFORNIA—PANEL II

Presenters

Ms. Lourie Campos

Mr. Thien-Nhien Luong

Ms. Gwendolyn Favila-Penney

Mr. Ron Zeno

MS. LOURIE CAMPOS

Background

Ms. Campos is a Policy Analyst at the Community Health Partnership, a consortium of community clinics in Santa Clara County that also runs public health programs, including the State-funded Breast Cancer Early Detection Program. Her remarks were offered from a survivor’s perspective. Ms. Campos’ father was diagnosed with colon cancer in 1980 and died in 1991. In 1997, Ms. Campos was diagnosed with stage III endometrial cancer. In 1999, her brother was diagnosed with colon cancer.

Key Points

- Ms. Campos’ father was a conservative, private Filipino who did not want people to know that cancer had invaded his life. He was ashamed and afraid that his family would be ostracized by their tight-knit Filipino community. Before he died, her father gave her a list of things to do and people to contact at the time of his death; at the end of that list was the statement: “Do not mention my sickness.” In some sectors of the Filipino community, cancer is considered a contagious disease. Ms. Campos honored her father’s wishes for a while, but it became increasingly difficult to do so, especially after her own, and then her brother’s, cancer diagnosis.
- Because of the type of cancers that she, her father, and her brother developed, and because they were all diagnosed in their thirties, there has been speculation that her family suffers from Lynch Syndrome, or Hereditary Nonpolyposis Colorectal Cancer (HNPCC). The family has considered the possibility of performing genetic testing on Ms. Campos’ niece. However, the family has decided not to test her until substantial laws exist to protect her from discrimination by insurance companies and future employers. Instead of testing, the family is diligent in the niece’s health care, and her pediatrician has been made aware of the family’s history of cancer.
- California has one of the highest uninsured rates in the country. A report issued recently by the Women’s Foundation gave California a *D* for health care for women and girls—particularly low-income minority women and girls. California ranks 33rd in providing Pap smears to detect cervical changes that may lead to cancer.

Recommendations

- Medical and health care professionals need to recognize that culture plays an important role in whether individuals will access health care services. If a particular cultural group believes that cancer

is contagious, deserved, or shameful, and health professionals lack the knowledge or tools to deal with these perceptions, people will not seek cancer screening services and providers will wonder why.

- Laws to ensure the privacy of health care records are needed to protect patients so they will feel safe in accessing potentially lifesaving genetic tests and treatments.
- Comprehensive legislation is necessary to ensure equal access to health care, especially for people who have low incomes and are medically underserved. The health care system must be more culturally and linguistically appropriate, and the diversity of health professionals must be increased at all levels.

MS. THIEN-NHIEN LUONG

Background

Ms. Luong has worked with the Vietnamese population on various health issues since 1993. Recently, she was appointed to chair a community coalition called the Vietnamese Reach for Health Initiative, which consists of nine community-based agencies.

Vietnamese have been settled in the United States since 1975. Census data from 1990 indicated that approximately 614,000 Vietnamese were living in the United States. It is estimated that as of 2000, there are approximately 915,000 Vietnamese living in the United States. By 2030, the Vietnamese population is expected to grow to about 4 million people.

About half of the U.S. Vietnamese population resides in California. One in every hundred Californians is Vietnamese. Three of every hundred residents in Orange County are Vietnamese, and five of every hundred residents in Santa Clara County are Vietnamese. Estimates of the Vietnamese population in California for 2000 are about 400,000. By 2030, Vietnamese are expected to become the largest Asian/Pacific Island population in California.

Key Points

- Vietnamese men have high rates of liver cancer and stomach cancer. Vietnamese women also have high rates of these two cancers, as well as high cervical cancer rates.
- According to data culled from various sources—including a community forum conducted in 2000—patient-related barriers, such as lack of knowledge about cervical cancer and the Pap smear as a screening test, contribute to the high cervical cancer rates. Only about a third of Vietnamese women living in the United States receive Pap smears.
- Fear of cancer was another important factor identified in the community forums and from Ms. Luong's speaking with her own family members and friends afflicted with cancer. Within the Vietnamese community, people who contract cancer are believed to have been cursed because of "bad karma." Financial burdens on the family and fear of dying also were cited.
- Research from the Office of Human Relations of Santa Clara County (Summit on Immigrant Needs and Contributions) indicates that about 21 percent of the Vietnamese population is uninsured. Approximately 42 percent of those studied expressed the need for specific medical care. The Santa Clara research further indicated that 75 percent of Vietnamese women prefer to go to a Vietnamese physician, but Vietnamese physicians do not routinely offer or recommend Pap smears to their patients. The reason for this is unclear but may be a lack of knowledge or because most Vietnamese physicians who practice within the community do not belong to an HMO and therefore lack access to a reminder system. Lack of time with patients may also be a factor; there is not enough time to explain to patients about the need to get a Pap smear or even to inform them about their medical

histories or diagnoses. Vietnamese women surveyed also indicated that they prefer to have female physicians.

- System-related barriers include lack of low- or no-cost Pap smear services in Santa Clara County for low-income and uninsured women. Confusing and cumbersome paperwork, different reporting requirements, and low reimbursement rates discourage clinics from offering services under the Breast and Cervical Cancer Control Program (BCCCP) or the Breast Cancer Early Detection Program (BCEDP).

Recommendations

- To increase utilization of health care services in the Vietnamese community, services must be less expensive and must include health care providers who speak the language.
- Changing people's behaviors to increase their knowledge is useless without access to the health care system. Santa Clara County currently offers no free or low-cost Pap smear screening services that would enhance access.
- The Federally funded BCCCP is run separately from the State-funded BCEDP. These programs should be merged in order to serve Vietnamese and all women as whole people.

MS. GWENDOLYN FAVILA-PENNEY

Key Points

- Many people who are treated in Alameda County fail to follow recommended treatment procedures and may drop out of the medical care system altogether. Particularly within Asian and Hispanic communities, significant barriers prevent a large majority of these populations from receiving quality or even adequate cancer care. As a result, patients do not enter the health care system until their disease is advanced.
- In Asian communities, barriers are related primarily to language and religion. Most Buddhist clients will go to their temple to pray for cures rather than seek medical treatment. Strong past and current beliefs and past cultural beliefs hold that talking about cancer to any person outside one's immediate family will bring bad luck to the family. People are afraid to be around someone with cancer and beliefs endure that herbs, acupuncture, and special foods—such as turtle soup and black chicken—will cure cancer.
- No non-English-speaking woman should wake up and realize that her breast is missing, never understanding her diagnosis.
- The poor and working poor should not have to choose between needed medical treatment and feeding their children.
- The Hispanic community faces barriers that vary depending on ethnicity, education, and immediate locality. These barriers include linguistic challenges, shame about a cancer diagnosis; beliefs and taboos (for example, touching the body is a forbidden, dirty act); sexual issues (such as fear that if a woman has a breast removed, her husband will find her unattractive and leave her for another woman); cultural beliefs that reinforce the notion that emotional support should be handled through the family and that “outside” support is unnecessary; and issues around transportation, childcare, and immigration status.

Recommendations

- The barriers noted should be addressed through increased funding for: language services, transportation, and childcare; advertising and support for community organizations in appropriate languages; training for health care professionals about the cultural beliefs of the different ethnic populations with whom they work; and legal representation and practical support issues.

MR. RON ZENO

Background

Mr. Zeno was diagnosed with head and neck cancer in March 1998. He was advised to undergo three surgeries, including a radical surgery that would have left him with limited use of his right arm due to removal of several key nerves. Subsequent consultation with a radiation oncologist resulted in a less invasive procedure, followed by radiation therapy. Mr. Zeno's wife is an oncology nurse at a hospital.

Key Points

- When Mr. Zeno asked his original surgeon for pain medications, the doctor expressed a concern about drug addiction. Mr. Zeno believes this response reflected an unjust stereotyping of African-American men. Once people receive this kind of response from a doctor, they tend not to trust the medical establishment and may not return for further treatment.
- Mr. Zeno has private health insurance and was treated at a private hospital with an excellent reputation, but he did not receive adequate support to deal with his cancer.
- During his treatment, Mr. Zeno searched for a cancer support group for men. The only group he could find involved a 25-minute drive to a suburban community where, in the past, African Americans were not particularly welcome. Eventually, he joined a group that met at the hospital at which his wife worked.
- Mr. Zeno cited examples of possible institutional racism, including the manner in which his doctor told him about his cancer diagnosis. He believes that had he been Caucasian and privileged, he might have been treated better; his initial symptoms might have been taken more seriously; and he might have been diagnosed at an earlier stage.

Recommendations

- Institutional racism and class stereotyping impact the provision of health care in the United States; measures should be taken to deal with the resulting obstacles.
- More education and support are needed for men with cancer, particularly African-American men and other men of color.

DISCUSSION—STATE OF CALIFORNIA—PANEL II

Key Points

- According to current statutory language, a clinic or system cannot have both a BCCCP and a BCEDP contract. This requirement limits the availability of cancer screening services for women.
- The BCCCP requires that clinics estimate the number of women they will screen. In 1996, the Indian Health Center of Santa Clara Valley exceeded its estimate and was required to be financially responsible for breast screening and diagnostic services provided to those women over the estimated number. This arrangement imposes a financial burden on clinics.

- Santa Clara County has developed a pilot project that would use BCCCP money for cervical cancer screening only and use only BCEDP money for breast cancer screening. This approach should maximize the impact of Federal dollars for cervical cancer screening, since California has a strong State-supported breast cancer screening program.
- The Community Health Center in Santa Clara County discontinued its association with BCCCP and did not reapply for the contract because of the paperwork involved and the low reimbursement rate. BCCCP does not provide money for infrastructure, such as health education and outreach, and reimbursement does not cover the cost of services provided, creating a financial strain on community health centers. These problems will destabilize the health care safety net. Reimbursement must cover costs.
- It is difficult to secure treatment services for low-income, uninsured women—some of whom are undocumented aliens—who have been diagnosed with breast cancer through BCEDP or BCCCP. Hospitals cannot afford to provide treatment for these women because cancer treatment is expensive, and a provider can donate only so much care.
- The California Breast Cancer Treatment Fund covers only 18 months of treatment. Funding for the screening program is tied to tobacco sales in the State. Although the decreasing number of tobacco smokers is a positive trend, this development raises questions as to the number of women this program will be able to screen.
- Alameda County has large, diverse Asian populations, including Chinese, Vietnamese, and Korean communities. Some barriers to care have been overcome by approaching community matriarchs and involving them directly with health care providers. This partnership has included teaching health care professionals about cultural beliefs and implementing input from focus groups. Approaching these communities with the assistance of someone of their own ethnicity has proven successful.
- Information should be made available in a person's language. Messages are more likely to be incorporated into behaviors if those messages are delivered by people viewed as responsible persons in the target communities.
- The problems of poverty and lack of insurance must be confronted. These problems are made more complex by diverse populations with belief systems and values that impact whether care will be sought and whether follow-through will occur. One way to accomplish this goal is to provide culturally sensitive, culturally competent training for medical providers within medical institutions and across the health care system. The Federal Government should provide funds for pilot projects in local communities that would allow those communities to ascertain the most effective way to reach their populations. Medical school scholarships should be provided for minority students.

STATE OF ALASKA

Presenters

Ms. Anne M. Gore

Ms. Marcia Hastings

Dr. Gregory G. Marino

Ms. Theresa Damian

Ms. Mary Kailukiak

Ms. Paula B. Henry

MS. ANNE M. GORE

Background

Size and geographic distances make Alaska unique. Alaska covers an area of 586,000 square miles, with 3,000 navigable rivers and 3 million lakes, the largest of which covers 1,000 square miles. There is one road system in and out of Alaska. Some cities are located on that road system, but most are not. Alaska has 14 times as many planes as any other State; one of every 58 residents is a registered pilot.

In 1976, Ms. Gore's mother was diagnosed with breast cancer and had to fly out of state for her mastectomy and treatment, as did Ms. Gore's sister when she was diagnosed with pseudomyxoma peritonei (PMP) 20 years later.

Key Points

- Nearly all major medical services are now available in Anchorage, which is the largest city in the State and in which half of the State's residents (almost 260,000 people) live. However, people must fly from all over the State to access those medical services. The definition of *access to care* in Alaska is different from the definition of that concept in other States. It is challenging merely to get to a place where services are available. Often, *access to care* means leaving home and, because of the distance and cost, leaving one's family and support system for an extended period of time.
- The three hospitals in Anchorage and physicians throughout the State donate their time to cancer patients unable to pay the cost of their care. However, while many physicians expect to donate their time, they cannot provide the costly yet necessary medications for cancer treatment. Medical services for cancer treatment are not donated for destitute Alaskans because programs are available for them. It is to the underinsured and uninsured people who cannot afford their cancer care that hospitals and physicians donate their time.
- Physicians who work with underserved Alaskans in Anchorage have noted consistently that nearly all of their cancer patients present at later stages of disease. Even though most of these people receive the treatment they need, the lack of affordable health care in Alaska means that people cannot afford basic health screenings or preventive health care.
- Programs like the BCCEDP do not address the underlying problem of unaffordable preventive health care, education, and medication.

Recommendation

- Affordable programs are needed to increase access to cancer screening services and preventive health care.

MS. MARCIA HASTINGS

Background

As the oldest and largest women's membership organization in the country, the YWCA serves more than 2 million women and girls across the Nation. The YWCA of Anchorage was incorporated in 1989. The mission of the "Y"—to empower women and girls and to eliminate racism—guides its development of programs for health, fitness, and social justice.

In the early 1990s, the YWCA of the U.S.A. played a role in one of the first successful public/private/not-for-profit partnerships with the CDC and Avon. The purpose of this partnership was to find medically underserved women in need of breast and cervical cancer screening to participate in the CDC Breast and Cervical Cancer Early Detection Program. Avon's Pink Ribbon campaign dedicated funds to the YWCA of the U.S.A.'s ENCORE^{plus}® programs to be used for outreach education, referral to free or low-cost screening, and other enabling services—such as transportation and support services.

Key Points

- The ENCORE^{plus}® program is an agent for access. The YWCA has a proven track record in reaching and serving women and girls who are medically underserved, uninsured or underinsured; ethnic minorities; low-income; lesbian; and/or elderly.
- Recent community focus groups of uninsured and underinsured people provided information for a report that was recently submitted to the Anchorage Access to Health Care Coalition. Access to specialized care and prescription drugs were the health care needs of greatest concern, with safety net programs hard to find and even more difficult to access. An insurance program through a community partnership called Health Access Promotion Initiative (HAPI) and the ENCORE^{plus}® program were cited as two sources of aid in accessing and receiving health care. However, focus group participants stated that all programs fell short in providing access for individuals with chronic diseases.
- Barriers to health care and screening for underserved and uninsured Alaskans include inadequate financial resources, distrust of the health care system, lack of relationship with a provider, lack of established health behaviors, skepticism concerning government programs and health care systems, low literacy, and lack of information available in a first language.
- When the ENCORE^{plus}® program began outreach efforts to offer BCCEDP screening services, attitudes were less than enthusiastic. Many women were grateful for the resources that provided annual preventive screening exams, but many more displayed fatalistic attitudes about their health in general and, in particular, about their ability to pay for their health care. “I don’t want to know” was a common comment from women who were offered free screening services. They were concerned that they would not have the resources to do anything about positive results; they were concerned about losing health coverage if they switched jobs; and they were concerned about the expense of treatments that would leave their families in significant debt.
- Even when patients are without resources, private physicians donate time, and hospitals write off what they can. However, Alaskan women without insurance are incurring huge debts for their chemotherapy, radiation therapy, and prescription drugs.
- The Indian Health Service can serve as a model of appropriate and effective care.
- Nonprofit organizations and creative partnering are cost-effective ways of ensuring that education, information about resources, and access to health care are available to those most in need.

Recommendations

- Implementing community programs that provide health information and offer navigation services is critically important. Sometimes women want regular preventive care but need help scheduling an appointment, getting to the clinic, or accessing funds to pay for basic services.
- Funding intervention programs in a continuous and cost-effective manner is important. Creative partnering and community collaborations are serving as an important means to early detection of disease, as demonstrated by the CDC/Avon/YWCA partnership.
- Small businesses should join together to access group insurance programs in the same manner and for similarly lower rates as large corporations. A plan should be developed for pooling resources so that low-income populations can tap into existing benefit packages.
- Insurance benefit packages should be uncomplicated, easy to use, and affordable.

DR. GREGORY G. MARINO

Background

Dr. Marino's practice is dedicated solely to the care of Native Americans with hematologic disorders and cancer. As recently as 50 years ago, cancer was a rare disease among Native peoples; there is no word for *cancer* in the Native languages. Today, cancer is the leading cause of death among Alaskan Natives, whose cancer death rate is the highest of all ethnic populations in the United States.

Key Points

- Reasons for the high cancer rate among Alaska Natives include increased average life expectancy (three out of four cancer cases occur in people older than 50), high rates of tobacco use (lung cancer is the leading cause of cancer death), and the presence of persistent organic pollutants in the Arctic and sub-Arctic environment (studies are in progress to discover the relationship between these pollutants and cancer).
- Many of the cancers in Alaska appear in familial clusters—particularly breast, colorectal, and gastric cancers. Genetics may play a role in this phenomenon, but appropriate studies have not been conducted, and trained people are not yet available to conduct the appropriate followup counseling that is required when such clusters are identified.
- Among non-Native care providers, a lack of understanding exists about the cultural imperatives surrounding the concepts of cancer, cancer research, and cancer screening. Cultural factors also may adversely affect pain control and the ability of providers to alleviate the suffering that accompanies cancer.
- Barriers to cancer care in Alaska include the fact that English often is a second language, if it is spoken at all; that people with cancer are feared by their families and by other members of the village and are considered outcasts; and that their small, remote communities are scattered over many square miles of roadless land where access is by snowmobile in the winter or by costly air travel that is subject to weather conditions.
- The primary health care providers in the villages are the Community Health Aides (CHAs), highly motivated people who often possess only a high school diploma and less than 6 weeks of training. This training is limited to the acute care of common problems; CHAs are not equipped to care for cancer patients or to provide cancer screening.
- Little or no cancer information is culturally sensitive to Alaska Natives. The telephone number 1-800-4-CANCER is virtually never called by anyone in these communities.
- Little or no cancer screening is carried out at the village level. Mammography and colorectal cancer screening, specifically sigmoidoscopy and colonoscopy, are provided only at major service centers. The cost of travel to these service units often exceeds the cost of the procedures themselves.
- Depending on the regimen, the Alaska Native Medical Center in Anchorage can manage some cancer treatments for patients at the “bush” (outlying small communities) hospitals, but dose-intensive regimens and regimens with significant potential for toxicity are not given to patients in the bush because those patients may not be able to access the health care system quickly enough if they have significant problems.
- The majority of patients with incurable diseases, including cancer, wish to return to their families and friends in their home villages. Palliative care of these patients and care of their families is the most important and the most difficult challenge for effective cancer care in the State of Alaska. Poor palliative care delivery is the most powerful barrier to cancer care, the most powerful barrier to cancer screening, and the most powerful barrier to cancer research and cancer treatment because of the lack of confidence untreated suffering creates in the system as a whole.

Recommendations

- Adequate training and education are needed at every level of palliative care, including training and education for nurses and physicians at service units, pharmacists serving the service units, mid-level providers, and CHAs. Patients and their families also need to be educated.
- Palliative care needs to be coordinated such that a system is developed to handle the logistics of palliative care in the bush. For example, it takes 2 weeks for a dose of morphine to reach most patients in their home villages if they run out of pain medication. Effective and timely relief from suffering should be the foundation upon which any cancer care program is built.

MS. THERESA DAMIAN

Key Points

Ms. Damian was diagnosed with breast cancer and underwent a mastectomy. She had eight sessions of chemotherapy at the Bethel Regional Hospital, each time flying to and from her home in the small town of Alakanuk.

In March 2000, her husband was diagnosed with lung cancer. He underwent five chemotherapies and 6 ½ weeks of radiation. During his treatments, the couple had to remain in Anchorage. Clifford Damian died on September 24, 2000.

In May 2000, Ms. Damian's 26-year-old daughter was diagnosed with breast cancer. After she had a mastectomy in June 2000, she went through eight sessions of chemotherapy at the Alaska Native Medical Center, receiving the last treatment in December 2000. At this time, she is doing well.

MS. MARY KAILUKIAK

Background

In 1995, Ms. Kailukiak was diagnosed with breast cancer; she discovered a lump in her breast while she was breast-feeding her sixth child. The public health nurse checked and measured the lump and made her a mammogram appointment at Bethel. After the mammogram at Bethel, Ms. Kailukiak went to Anchorage for a biopsy. She stayed in Anchorage for her surgery appointments and implant. It was most difficult to leave her six children without telling them about her health problem. Ms. Kailukiak took her first cycle of chemotherapy before leaving Anchorage and continued the rest of the seven cycles at Bethel. She also took tamoxifen for 5 years.

During this period, she lost her eldest son.

In 1997, Ms. Kailukiak had a recurrence, first found in a lymph node under her left arm. For each session of this round of chemotherapy, she would have to be in Anchorage for a week. Ms. Kailukiak often took one of her children with her. After her treatments were completed, she traveled to Seattle in the summer of 1998 for stem cell collection; her younger sister accompanied her.

Ms. Kailukiak thanked the health aides, nurses, and doctors at the Alaska Native Medical Center, her Blue Cross insurance, and her Higher Power for making it possible for her to be at this meeting.

MS. PAULA B. HENRY

Background

Ms. Henry discovered a lump under her arm while she was taking a steam bath. The following year, when she went to the clinic, she was told to go to Bethel Regional Hospital, where she was examined, given penicillin to take for 10 days, and told to come back if the lump did not go away.

Ms. Henry then sought care in Anchorage, where she was diagnosed with two different cancers. She was advised to undergo a mastectomy—which she did, recuperating in Anchorage for about 6 weeks.

Ms. Henry's first chemotherapy was administered in Anchorage and was followed by seven cycles at Bethel. Every year thereafter she returned to Bethel Hospital, but since the hospital had inadequate equipment and no cancer specialists, she decided to go to Anchorage for her followup care.

DISCUSSION—STATE OF ALASKA

Key Points

- The problems of palliative care and screening are linked. People must have confidence that they will be taken care of when they have a serious illness. The mechanics of palliative care in the villages are extremely difficult. Patients who are going to die of their disease have a right to have their symptoms managed appropriately. Most cancer patients in Alaska do not want to die in Anchorage; they want to return home.
- Health aides may fear the potent narcotics that cancer patients take because of the potential for addiction and fear that the drugs will be stolen or misused. In addition, patients with escalating pain often run out of their 30-day supply of pain medication well before the end of the month, and it may take the health aide as long as 2 weeks to fly in an adequate dose of pain medication for those patients.
- A palliative care coordinator could track patients who go home to the bush and would have the experience and training in medications and techniques to manage a palliative care program effectively. Part of the program could include an educational component that is taken to the bush, to other service units, and to the villages to further teach both the Community Health Aides and the people not to fear the drugs. Cancer patients must understand that they do not have to die or live with pain and that their symptoms can be managed.
- Cancer prevention and education have always been a low priority, and funding has never been adequate to provide those services throughout both Alaska and the Nation.
- Treatable cancers often are managed well and at little or no cost to patients by both hospitals and the private medical community. People are not denied access to care because they lack the resources to pay. Clinicians and hospitals are willing to write off some charges and/or work out payment plans. However, even with free and discounted services, cancer patients are nonetheless placed in perilous financial situations, incurring expenses that they will have to pay over time after their treatment is complete.
- The Indian Health Service (IHS) is being taken over by the Alaska Native Tribal Health Consortium, with support from 13 major corporations in Alaska. The Alaska Native Tribal Health Consortium guarantees care for all those eligible. The Consortium is committed to providing primary care physicians for everyone who is eligible for care, but continuity of care is difficult to maintain in the

bush because of high physician turnover. Once patients access specialty care, especially in Anchorage, they receive state-of-the-art services. No one is turned away, and nothing is withheld from any patient for financial reasons. Providers like this system because, among other things, procedure coding is done only for statistical purposes, not to support the system.

- The State of Alaska Department of Public Health maintains a solid infrastructure and would be the stakeholder that implements evidence-based programs. Geographic distances in Alaska are enormous, but the State addresses this issue through its outreach programs.
- The Health Care Financing Administration (HCFA), CDC, and the Federal Government need to include Alaska Native and Native American women in the Breast and Cervical Cancer Treatment Act. These women are excluded because they have been deemed to have “creditable coverage” through the IHS. The IHS is underfunded and offers less-than-optimal services.

REMARKS—DR. MARJORIE KAGAWA-SINGER, UCLA SCHOOL OF PUBLIC HEALTH AND ASIAN AMERICAN STUDIES

Key Points

- In the Los Angeles County school district, more than 120 languages are spoken; 224 languages are spoken statewide. Multiculturalism is a fact of life in the United States, but the health care system continues to be based on a monocultural model.
- Race and ethnicity as social and political constructs have had significant impact on the use of health care. Extensive documentation exists in the literature on disparities in the receipt by ethnic minorities of invasive cardiac procedures, kidney transplants, pain control, and cancer control programs.
- In 1972, the U.S. Office of Management and Budget developed the categories that are used today for demographic classification: non-Hispanic white, African-American/black, Hispanic/Latino, Asian/Pacific Islander, and American Indian. However, no scientific indicators support the concept that separate racial groups exist; these groupings are social and political constructs.
- Though not a biologic reality, “race” is important in this country because of racism in or the racialization of health care. The assertion of power and ego fulfillment at the expense of others according to the color of their skin affects health care through differential treatment. Practitioners provide care according to a hierarchy of factors such as a person’s phenotype, gender, and socioeconomic status.
- When an individual is more culturally and physically similar to the dominant group, stigmatization is minimal, and assimilation tends to be more rapid. Individuals who differ more, both in physical attributes and culture, tend to encounter more stigmatization.
- Social forces have insidious and direct effects on health care practice. One implication in cancer care is that psychosocial support may be offered inconsistently, negatively impacting both communication between practitioner and patient and the assessment of need for and the offering of psychosocial support. A study designed to assess physician referral patterns for invasive diagnostic procedures for cardiovascular disease found that outcomes were most optimal for Caucasian males, second most for African-American males, third for Caucasian females, and fourth for African-American females. This pattern is consistent with morbidity and mortality patterns for cardiovascular disease.
- A study by David Wellish and Dr. Kagawa-Singer looked at Chinese-, Japanese-, and Anglo-American women with stage I and II breast cancers who were eligible for breast-conserving therapy (lumpectomy). Because the treatment prevented them from resuming their family roles more rapidly,

the Asian-American patients chose lumpectomy and radiation at a much lower rate than did Anglo-American women.

- Acculturation affects behavior, and the variations within each ethnic group must be understood. It is critical to elicit relevant cultural information when reaching out to communities.
- In outreach efforts, the positive aspects of culture should be used to communicate the desired message. One example is the use of the “circle of life” concept in health messages targeting Native Americans.
- A multicultural, ecologic model that incorporates the environment, social institutions, social networks, families, and individuals across the lifespan will help improve cancer outcomes. Examining the dynamic nature of these interactions will help in understanding how the nature of each variable changes as a result of the interaction. Rather than attempt to tease out the individual contributions of, for example, ethnicity and income, one must examine the interactions of these variables and their differential impact on particular groups.

Recommendations

- The cultural beliefs of ethnic minorities in the United States should be studied to recognize the effect of minority status on the behavior of patients and practitioners.
- Differential treatment is a reality, but health care practitioners often are unaware that they are treating patients differently for reasons not related to their disease. The existence of this problem should be acknowledged, and it should be addressed in scientific investigations in order to determine how this issue affects outcomes.
- Cultural variations in treatment choice must be studied within the context of differential treatment. The Institute of Medicine (IOM) report on the unequal burden of cancer among ethnic minority populations indicates that the meaning of cancer and methods of coping with cancer must be studied within each ethnic group. The effect of cultural beliefs and practices and minority status on treatment choice also should be studied.
- The cancer-protective factors related to diverse cultural beliefs and practices should be examined. Many ethnic groups have cancer incidence rates lower than those of Caucasians for certain cancer sites. Cultural beliefs, practices, foods, and habits shown to be protective against cancer could be disseminated and promoted to all population groups to lower everyone’s cancer rates.
- Research should be based on unquestioned answers rather than the more usual unanswered questions, and the assumptions and implicit value system underpinning current research should be examined. The multicultural focus of cancer care must be expanded to ask new questions and must incorporate the reality of minority status in research and community outreach efforts.

STATE OF OREGON

Presenters

Dr. Nathalie Johnson

Ms. Betty Byrtus

Dr. Donald Austin

Ms. Peggy Carey

Ms. Corliss McKeever

DR. NATHALIE JOHNSON

Background

As Medical Director for Legacy Cancer Services and a practicing surgeon, Dr. Johnson treats many women with breast cancer. She talked with staff and clients at Legacy Cancer Services to identify key issues to report at this meeting.

Key Points

- The two large groups that present with many access-related problems are the working poor (regardless of ethnic background) and the “in-betweeners”—people who are not yet 62 years old (and, therefore, do not qualify for Medicare)—who are working but have minimal insurance coverage, and who do not qualify for any of the available medical or general assistance programs.
- Inherent biases can compromise services and care, but using coordinated teams can assist in dealing with those biases. Instead of a single physician seeing patients and making decisions, several physicians may treat the same patients and discuss their care in conjunction with caseworkers who address socioeconomic issues that can create barriers to care. For example, a senior caring for a spouse who has Alzheimer’s cannot come to a health appointment because there is no one to watch the spouse during that time. A social worker could take care of such a problem with a few phone calls, whereas a physician would have no idea how to provide that service.
- Funding and reimbursement are so inadequate that many physicians in Oregon cannot earn a living. Even though they have insurance, many patients lack primary care physicians. Because of low reimbursement rates, local physicians are beginning to drop Medicaid, Oregon Health Plan, and some HMO patients. In addition, physicians and hospitals cannot afford to update their technology when the bottom line is heavily impacted by further reductions in reimbursement rates.
- Patients’ views of barriers to access include financial concerns, location of care, and education about the body and health. Trust is an important issue, especially for people in lower socioeconomic categories and for ethnic minorities, who often feel that providers neither care about them nor see them as real people and do not offer them the best care.
- The biggest opportunity for change is in reaching children and using the health education system. Children should be taught not only about sex education, but also about nutrition, physical activity, cancer, and how to examine their bodies. Education, particularly of younger children, also offers a significant opportunity to affect family behaviors and knowledge.

Recommendations

- Coordinated health care services and a holistic, team approach to care should be adopted.

- The insurance industry needs better policing. Chief Executive Officers (CEOs) of insurance companies should not get bonuses for savings they generate when patients are going without care or are not being referred because of cost-related pressures. Broader coverage, to include rural residents (especially seniors in rural areas), is needed to provide better access to health insurance.
- Support is needed for outcomes analysis in order to evaluate the effectiveness of programs. For example, an intensive tobacco education program with a middle school in Portland lasted for the 4 years of the grant period, but tracking the program's effect on smoking rates in high school was not possible because funding was not provided for evaluation.
- Public support programs need to be more flexible. For example, a woman with breast cancer who was receiving chemotherapy after a lumpectomy returned to work and was earning slightly more than the income ceiling to qualify for the Oregon Health Plan. As a result, she was dropped from her only health insurance and could not afford the prescribed radiation, and her cancer recurred.

MS. BETTY BYRTUS

Background

Ms. Byrtus has undergone two mastectomies, chemotherapy, a hysterectomy, adhesion removal surgery, two cataract surgeries, lung bronchoscopy, a colonoscopy, and a variety of x-rays, CT scans, bone scans, and specialist visits. She and her husband were insured only by a private plan with high deductibles, and her treatment has left her with a \$30,000 medical bill loan and a first-hand understanding of the term *underserved*.

Coastal County is 100 miles long and has the highest per capita breast cancer mortality rate in Oregon.

Key Points

- Five years ago, Coastal County's small hospital received a 3-year Federal grant to provide early detection education programs for breast cancer. The education programs, mobile mammography unit, patient support, and hospice participation of the Curry Breast Health Network were so successful that when the grant ended, the hospital decided to continue the Network. However, due to budget constraints, the Network had to be operated on a part-time basis, and the State decided to discontinue the mobile mammography service in two other towns in the county, each 30 miles from the hospital in different directions. In response, Curry General Hospital recently purchased a second stationary mammography unit, placing it in a private physician's office and staffing it one day a week with a technician who travels there from the hospital.
- To help reach underserved individuals, funds for early detection programs have been raised through Avon and Susan G. Komen Foundation grants, annual survivor awareness fashion shows using survivors as models, and a special dinner show at the local performing arts center. NCI and ACS materials are utilized widely. Support is provided by local media through public service announcements, press releases, and local television programming on early detection.
- The "unders" involved in the lack of cancer diagnosis and treatment for the 22,000 residents of Curry County are: *undereducated*, *underinsured*, *underemployed*, *undervalued*, *understaffed*, *underreimbursed*, and *underavailable*:
 - *Undereducated* in the importance of early detection. Many seniors were raised not to talk about sexual organs—not even to a spouse. Doctors say that some women feel so uncomfortable during a breast exam that they do not allow a thorough one; these same women are less likely to do breast self-exams.

- *Underinsured* because employers no longer provide health insurance coverage. Since insurance rates have skyrocketed in recent years, many companies cannot afford to absorb the cost of providing coverage for their employees and, particularly, for employees' dependents. Government mandates that companies with a certain number of full-time employees provide health insurance benefits have resulted in companies hiring more part-time workers, not in more individuals and families receiving health insurance coverage.
- *Underemployed* by circumstance. Many workers along the Oregon coast are part of displaced logging and fishing industry families who had been employed successfully for generations. These people now find themselves not only unemployed and uninsured, but also struggling to learn new trades to provide the basic necessities. They are so stressed in response to the changes already taking place in their lives that when a possible cancer symptom occurs, they feel they have no choice but to ignore it and hope for the best. Free cancer screening is available, but surgery and treatment are too overwhelming to contemplate.
- *Undervalued* by insurance companies. Many insurance companies are refusing to sign contracts with rural hospitals and physicians because the return on their money is not substantial enough in areas without large numbers of premium-paying patients.
- *Understaffed* local medical facilities. Recruiting full-time specialty physicians and nurses is cost-prohibitive for small tax-based facilities like Curry General Hospital, so the hospital has partnered with a visiting oncologist who travels 100 miles once a month to see cancer patients in the Curry area. One specially educated nurse administers chemotherapy to several patients. The large majority of cancer patients in Curry County must travel significant distances for their treatments and specialized medical care.
- *Underreimbursement* for rural physicians. In Oregon, urban providers are generally reimbursed at higher rates than are their rural counterparts. The costs of providing patient care are actually greater for rural physicians due to lower volume, lack of purchasing power, and higher freight fees.
- *Underavailable* screening opportunities. Because the cost of physician appointments is unaffordable for many residents of the county, Curry General Hospital partners with the County Health Department in cancer screening clinics and participates in health fairs. However, resources are not available to reach into the more remote inland areas of the county.

Recommendations

- Early detection programs should begin in high school so that young people will realize the importance of paying attention to changes in their bodies as they mature and will take this information home to the adults with whom they live.
- Insurance companies should reimburse all providers at the same rate, based on the services rendered and not on their ZIP codes.

DR. DONALD AUSTIN

Background

Oregon's population numbers 3.4 million. More than 93 percent are Caucasian. Hispanic whites make up less than 6 percent of the Caucasian population and are Oregon's largest ethnic minority. The Caucasian population also includes several other ethnic minorities, such as Russians and Yugoslavians/Bosnians.

The Cascade mountain range divides the State's environment and its population. East of the Cascades is mostly high desert that contains about 13 percent of the population but about 69 percent of the State's area, with an average population density of 6.5 persons per square mile. This population of about 440,000 lives in an area larger than the States of New York, New Jersey, Delaware, and Maryland and the District of Columbia combined. Much of the State has less than three persons per square mile, and three of Oregon's counties have less than one person per square mile, so problems with access to medical care and to medical specialties in Oregon are similar to those encountered in many areas in Montana, Wyoming, New Mexico, and Arizona. The area west of the Cascades includes Portland, the only major metropolitan area, with a population of 1.4 million residents—the majority of the State's population.

Oregon's Cancer Registry has been in operation since 1996, and the State Cancer Center (Oregon Health and Science University Cancer Institute) was NCI-designated in 1997. These two organizations are now building a cooperative relationship in population-based cancer research.

Key Points

- People with disabilities often do not receive the same cancer control services as do able-bodied people, due to mobility problems, cognition problems, and because providers are reluctant to deal with patients' disabilities. Preliminary results from a joint study linking the Oregon Medicaid file with the State Cancer Registry indicate that persons with disabilities are at higher risk for later-stage diagnoses, and some also are at higher risk for certain cancers, such as liver and lung cancers. This special population has not been targeted for cancer control programs, yet it is a vulnerable minority that constitutes between 10 and 15 percent of Oregon's population. In fact, mental health technicians who have worked with people with disabilities have stated that they encouraged these patients to smoke because it gave the caregivers a nonviolent way of controlling their behavior.
- Data from Quality Assurance committees for managed care organizations (MCOs) indicate that while providers do not oppose or disagree with evidence-based guidelines for preventive or maintenance care, many patients still do not get appropriate care. Financial concerns appear to be an important factor in provider behavior. In one instance, when providers or clinics were given a financial incentive for improving the performance level of certain procedures in their populations, the performance levels rose. When the incentives were then switched to support other procedures, the performance levels for the original procedures declined.
- Despite the large national investment in State cancer registries, the data necessary for monitoring the quality of care generally are not collected, and registry personnel usually are not linked with an appropriate body for conducting such evaluations.
- A complete disconnect exists between statewide or population-based surveillance and data collection and the provision of care. By contrast, in Canada, the provision of medical care and cancer surveillance activities are located within the same institutions.

Recommendations

- Research is needed on how best to meet the cancer control needs of special subpopulations, such as people with disabilities.
- A relatively small incremental increase in funding for cancer registries nationwide would allow appropriate data to be collected and analyzed to determine which treatments for particular site and stage combinations are provided in various subpopulations.
- Research is needed to identify quality-of-care measures for which data can be collected by record review and to develop policies establishing an appropriate body in each State to conduct quality-of-care studies.

- Research and development are needed to identify a system that can help provider practices run more efficiently, improve the quality of care for key evidence-based procedures, and reduce the need for multiple chart reviews by MCOs or other payers as they determine the level of care provided to a population.
- Although providers understand the need for cancer screening and patient education, patients often do not receive those services because of support system failures. Informatics and software systems research are needed to develop this support system.

MS. PEGGY CAREY

Key Points

- Physicians tend to practice what they were taught in medical school. Cancer specialists want to translate current research-based information into practice, but most physicians do not have time to read journal articles or have an academic discussion with a colleague. Time that used to be spent in those activities is spent seeing more patients in a day and trying to keep up with reporting, coding, and billing requirements. Physicians need time to continue their education and to take care of their patients.
- Patients do not receive advanced, research-based treatment from general practitioners. Oncologists should treat patients with cancer, and general practitioners should be trained to provide screening, promote early detection behaviors, and provide end-of-life care in the community. Receiving care close to home is important for patients, but receiving appropriate specialty care from an oncologist is of paramount importance, even if the patient must travel to receive that care.
- Screening is overused in some situations and for some diseases, without definite scientific support or consensus, thus creating confusion for patients and practitioners. Two examples are screening for prostate cancer and screening guidelines for breast cancer.
- Incentives are needed to encourage physicians and hospitals to participate in clinical research trials. Participating in clinical trials increases paperwork, exacerbates an already burdened system, and requires additional staff in already understaffed clinics and hospitals.
- New therapies are not applied consistently and therefore cannot be evaluated for efficacy. No quality assurance system is in place to evaluate the utilization of a treatment once it is beyond the research phase. Although some prospective planning is conducted by multidisciplinary groups at tumor conferences, no one tracks or evaluates compliance or outcomes.
- Cancer care is fragmented and confusing for patients and practitioners. Cancer care is multidisciplinary, requiring many referrals and a team of consultants. Patients and their families usually are the ones responsible for coordinating care. This situation creates a major barrier to access to quality care.
- “Turf battles” about procedures exist among specialists. The current dispute between general surgeons and diagnostic radiologists as to who should perform breast biopsies is one example.
- Entrepreneurial behavior is hurting the health care system. Duplication of services and technology is driving up health care costs, further preventing access and further fragmenting the health care system.

Recommendations

- An evaluation system is needed to encourage accountability and to promote use of proven interventions.

- A fundamental shift in reporting must be made—from ensuring accurate coding and billing to ensuring that patients are receiving appropriate care. Physicians spend an inordinate amount of time trying to understand reimbursement requirements; this time was previously spent on patient care.
- Standards of care or practice guidelines must be developed to measure treatment efficacy and ensure that patients are treated similarly according to current research-based findings—wherever they receive their cancer care.
- General practitioners should be supported in providing screening and preventive health services and should refer cancer care to specialists. Consistent screening guidelines should be developed.
- People need education on how to stay healthy and must understand what care is required—from screening through treatment—so they will know what questions to ask providers.
- Physicians should be assisted in obtaining accurate, timely cancer information. This could be accomplished by providing traveling teams of professionals, disseminating information through existing State organizations, and providing user-friendly Internet sites.
- Incentives should be created to encourage investigators and programs to participate in research trials. Adequate funding for support functions is necessary, and the paper burden must be reduced to ensure that investigational therapies are not provided outside the research setting.
- A process should be developed to reduce duplication of technology in any geographic location.
- Strong Quality programs should be developed, and treatment plans should be measured and evaluated. Every hospital measures sentinel events, but no one is measuring the quality of the care experience as a whole. Patients need a plan of care from diagnosis through treatment that is patient-centered, research-based, timely, and cost-effective.

MS. CORLISS McKEEVER

Background

In Oregon, people of color constitute 7 percent of the population, of which African Americans represent about half (3.2 percent of the total). Eighty-two percent of all African Americans in Oregon live in the Portland metropolitan area.

The African American Health Coalition formed in response to an inability to access the planning process for health in the State of Oregon. Coalition members are health professionals who banded together because their needs were not being addressed. After 10 years of operating as a volunteer organization, the Coalition became a nonprofit organization in 1998. It is now located on the campus of one of Oregon's major health systems.

Key Points

- The African-American community in Oregon is cut off from health care because of difficult access to health care systems. Access is defined as both external (i.e., getting into the health care system) and internal (i.e., how a patient is treated once inside the health care system).
- Because African Americans in Oregon do not feel respected within the health care system, they tend to keep appointments only when they absolutely must. They believe they are treated differently if they receive medical assistance. Other barriers include a lack of clinical trials for African Americans, lack of health education and prevention information, and treatment disparities related to race.

- A disconnect exists between the way information is transferred and how it is interpreted. For example, an event conducted as part of a high-risk pregnancy program revealed that the 15 women attending knew what trimester they were in (because their doctors had told them) but they did not know the meaning of the word *trimester*.
- Effective care and prevention require that information be delivered in a culturally sensitive manner and with respect. African Americans respond positively when services are delivered in what they perceive to be a culturally appropriate manner.
- Quality health care is crucial, but data on health care quality among African Americans in Oregon are difficult to interpret because of the small percentage of the population represented by African Americans. Survey data collected by the BRFSS telephone survey may not be statistically significant due to the small numbers of African Americans contacted using the survey's methodology.
- The African American Wellness Village unites more than 45 health care providers and more than 700 community members in a 1-day event based on free screenings and health education. Oregon's one mammography van came to this event and provided mammograms in a parking lot on site, but the van did not return because people were not preregistered, arrived late, and did not follow the required protocol. Out of more than 30,000 African-American women in Oregon, 49 were screened for breast cancer in 1998, and 48 were screened in 1999.
- Providing information to a community empowers that community. For example, in 1996, the Portland African-American community was unaware that it had the third highest infant mortality rate in the Nation, nor were they aware that African-American women have a lower incidence of cancer but a higher mortality rate. The more people know, the more they are willing to work for change.
- The African American Health Coalition has developed a strong relationship with the largest African-American church in Portland, with several other churches, and with two beauty salons. A training-of-trainers program will teach key people within these realms to provide health education and information to their congregations and clients. The Coalition is also developing similar relationships with area health care systems.

Recommendations

- Capacity should be developed in the community where it will remain after the grant period is over.
- Technical assistance and skills training—not just monetary assistance—should be provided to communities.

DISCUSSION—STATE OF OREGON

Key Points

- Federal programs that are time limited must have sustainability built in from the beginning, as part of the implementation plan for the entire program. Private interests or local foundations will become interested in sustaining programs that show positive outcomes.
- Even if enough money is available to run a program efficiently, there usually is not enough money to disseminate relevant information and market the program. State governments could encourage community coalitions to mobilize the community—which is their expertise—and then use their statewide presence to help disseminate information.
- Training and maintaining an adequate workforce of tumor registrars is a problem; most registries have vacant positions. Most of the registries in the United States, other than the SEER registries, started with local support and were poorly funded and of poor quality. This situation has changed; most

tumor registries now adhere to a common data set with common standards, producing a uniform surveillance system throughout the country. However, the data set is insufficient to monitor the types of care provided or to correct identified problems. A tumor registry is not a moneymaking service; it is an overhead expense for a hospital.

- Tools are not yet in place to measure quality of cancer care. Quality is measured not only by what should be done technically, but is also related to patients' subjective experiences. Patients who come from different cultures will evaluate quality differently. Many important components of cancer care quality have not yet been well defined.
- A significant shift in emphasis has occurred—from focusing on measuring care to concentrating on measuring cost. Treatment should be measured and evaluated first, and then the cost to provide care should be evaluated. Managing costs is not managing care. The Federal Government should police insurance companies by mandating regular reports to policyholders on the amount spent on administration versus the amount spent on patient care and physician reimbursement.
- Except for the largest employers, which have a greater choice of health insurers, most employers choose health insurance coverage based on which health plans will accept them. For example, a rural 24-bed hospital in Oregon had the “choice” of a single insurer, as that was the only plan that would insure it.
- Although they may be underinsured, most Oregonians have some form of health insurance—in part because of the State's unique Oregon Health Plan.
- Power and control are major issues for African Americans: having their voices heard, being able to put their agenda on the table, and being involved in health care decisionmaking.

STATE OF NEVADA

Presenters

Dr. Mary E. Guinan

Ms. Sandra Jackson

Mr. Lawrence Matheis

Mr. Ken Retterath

Ms. Maria Parra

DR. MARY E. GUINAN

Background

Nevada has the seventh largest land area of all the States. The population is small but is the fastest growing in the United States. The population doubled from 1990 to 2000, from 1 million to approximately 2 million people. Most of the population (1.3 million, or 66 percent) is concentrated in Clark County, which includes Las Vegas. Washoe County in the north (which includes Reno) has approximately 17 percent of the population, and less than 20 percent of Nevada's population is found in the other 15 counties. Many of the counties have no health care providers.

The State's main income is from gaming and tourism; taxes from those two enterprises support the State health budget. The tobacco industry has a great deal of influence in Nevada and has partnered with the casino industries, resulting in a strong alliance that the State has no internal incentive to challenge. Nevada ranks 50th of all States in investment in prevention, and Nevada has the seventh highest cancer mortality rate in the Nation.

Key Points

- Nevada has the highest smoking rates in the Nation for both men and women: 33 percent of the population smokes. None of the Tobacco Settlement money distributed to Nevada was funneled into smoking prevention. There is no comprehensive tobacco prevention program for the State and no incentive to create one.
- Nevada has the strictest tobacco preemption law of any State. A tobacco preemption law says that no entity within the State can have tobacco- and smoking-related laws stricter than the State laws. Therefore, weak statewide tobacco control laws cannot be superseded by county or local ordinances.
- No individuals or groups are lobbying for prevention services, and prevention has no natural constituency. Prevention funds are constantly cut out of budgets in favor of funding for treatment. Investment in prevention is a difficult concept to sell.
- The CDC-funded Breast and Cervical Cancer Screening Program is an effective screening program; however, Nevada has no funds for treatment for women whose cancer is identified through this program. Many personnel hours are expended in securing treatment for women with cervical or breast cancer.
- When a provider is identified who is culturally attuned to a minority population, the State frequently asks that provider to furnish services at no cost. These physicians quickly become overloaded with *pro bono* services.
- Needed integration of services in Nevada is thwarted by categorical funding. Most of Nevada's health services are structured in this manner. Community coalitions reach Nevada's underserved populations, but all are supported through categorical funding; thus, none of the money can be used to integrate services.

Recommendations

- The Federal Government, through NCI, CDC, and other agencies, should review the tobacco preemption laws with the goal of changing them. States will not make these changes on their own.
- No standards exist for treating people with smoking addictions. The Federal Government should disseminate widely the best practices or guidelines for treating the addicted patient. For example, in Nevada, many groups provide tobacco cessation services that might be considered alternative medicine, but there is no evidence as to whether or not these interventions (such as the nicotine patch and Zyban[®]) are effective.
- The Nevada State Health Department is currently investigating a cluster of leukemias in a small town. Creating and disseminating best practices and guidelines for investigating disease clusters would be helpful to the States.

MS. SANDRA JACKSON

Background

In 1993, Ms. Jackson was diagnosed with infiltrating, invasive ductile carcinoma. She had no family history of cancer, and she had been receiving regular mammograms.

Ms. Jackson had been employed for 12 years with a major bank in New York City and had full medical coverage at the time of her diagnosis. After her mastectomy and chemotherapy treatments, complications occurred, and she was diagnosed with asthma.

Subsequently, Ms. Jackson was unemployed and on long-term disability (an option she had chosen as part of her health insurance). She decided to move from New York City to Las Vegas because of her breathing problems. Although she completed and provided all the necessary paperwork in a timely fashion, Ms. Jackson's long-term disability insurance was terminated because Social Security benefits should have been—but were not—instituted within the usual 6-month timeframe. With no other income or medical insurance, she applied to the Nevada State Welfare Division for assistance.

In November 1995, Ms. Jackson was diagnosed with lung cancer. After volunteering with one of the major cancer organizations in Las Vegas, she started the Essence of Beauty Roundtable for women going through similar health-related financial problems. Medical insurance from the Nevada Welfare Department was her only source of medical assistance at this time.

Ms. Jackson was diagnosed in 1997 with recurrent breast cancer in her chest wall. She received 8 weeks of radiation.

Finally, in 1998, Ms. Jackson received notification that she was approved for Social Security benefits. At that time, her long-term disability insurance was also reinstated. She had been without income for almost 5 years.

Key Point

- With her partner, Ms. Jackson created a nonprofit organization, Courage Unlimited, with a mission to offer a positive forum for celebrating and improving life through health education and support. This outreach effort has produced a live cable television show featuring physician and survivor guests and guest radio spots; the organization also conducts other activities.

Recommendations

- During Ms. Jackson's recent test for sleep apnea, the technician conducting the test stated that she had a number of sleep apnea patients who had received chemotherapy. This side effect in cancer survivors should be investigated
- A provision should be added to the National Cancer Program to provide funding for any person receiving long-term disability insurance benefits who was terminated due to the Social Security Administration's inability to process the patient's application within a 6-month period.

MR. LAWRENCE MATHEIS

Key Points

- Approximately one in four working Nevadans or families is uninsured. Most work in the service industries, and many have moved to Nevada in the past 10 years, adding to the cultural diversity of the State.
- Nevada is one of only nine States that does not include a "medically needy" program in its Medicaid program. With the exception of those who are required to be covered by Medicaid, Nevada does not have health insurance eligibility for large numbers of indigent people or other people with medical conditions.
- In Nevada, as in most States, over half of the population is insured not under State law, but under laws passed by Congress. Those Federal statutes exempt self-insured employers and others from insurance rules.

- Physicians in Nevada have felt a need to provide leadership in the State on issues that otherwise would not be addressed, such as the problems of uninsured Nevadans and the tobacco issue. The Nevada State Medical Association helped form the Nevada Tobacco Prevention Coalition. Other issues tackled by physicians in Nevada include end-of-life care standards and related physician training; changing the State's rules governing pain management; breast cancer funding; prostate cancer screening and services to low-income men; off-label prescribing for cancer treatment; and adoption of a Patient Protection Act. Physicians formed the Nevada Center for Ethics and Health Policy to provide a resource for health professionals and to serve families of people needing end-of-life care.
- Laws passed by the State cover only the 50 percent of Nevadans insured under State law. Federal action is necessary to match the care provided in Nevada for Nevadans insured under Federal programs; currently, huge gaps exist in obtaining the same treatment for these people. For example, there can be very different outcomes for three patients with the same diagnosed cancer: one patient under an insurance plan that allows treatment with a standard-of-care prescription drug; one under an ERISA plan with a formulary that does not allow that particular drug; and one who is uninsured and unable to obtain the drug. Under such a scenario, one doctor can have three patients who each receive a different standard of care.

Recommendations

- Coverage for cancer care should be treated similarly to Medicare's end-stage renal disease (ESRD) program. Patients do not have to be 65 years old to be covered under this program; if they have end-stage renal disease and their kidneys are failing, they are automatically covered by Medicare. Medicare has provided a standard of ESRD care for the country.
- The Panel should propose a study on the impact of automatic Medicare eligibility upon a diagnosis of cancer. Although the cost may initially appear to be too great, costs may actually be reduced because private commercial insurance and employers will no longer have to cover cancer treatment, eliminating a major expense that drives up insurance premiums.
- Many cultural disparities can be addressed by making standards of care uniform and by holding all providers accountable under the same basic standards.

MR. KEN RETTERATH

Background

Adult Services of Washoe County is the county agency responsible for indigent care, primarily through the Health Care Assistance program. In 2000, approximately \$14.5 million was spent on indigent care, \$13.5 million of which was in the Health Care Assistance program. Adult Services does not provide medical services; it is a payer of services, and its programs are eligibility-driven.

Key Points

- Adult Services interacts with cancer patients primarily in the clinic settings. It works with the local health system and has eligibility workers and social workers located in the clinics. A General Assistance program provides cash assistance so that someone applying for Social Security Disability can receive financial help while waiting for approval of his or her application.
- Barriers to treatment for Adult Services' clients include limited transportation, lack of telephones, limited family resources, and language differences. The most significant barrier is "fatigue with government": People are tired of filling out forms, doing paperwork, and "jumping through the

hoops” necessary to get services. Fatigue with government leads to delays in diagnosis and treatment and to noncompliance. Clinics experience a no-show rate of approximately 60 percent for scheduled appointments—a direct result of disillusionment with the health care system.

- Categorical funding is among the biggest concerns of health care providers. Categorical funding allows providers to look only at certain body parts, so a thorough and holistic screening cannot be conducted.
- Another concern is the availability of funding for diagnosis without associated funding for treatment. Sometimes services are not provided because providers do not want to diagnose something they cannot treat, thus limiting the services available to cancer patients.
- The “in-betweeners” are cancer patients who have income from work, health insurance, a spouse and children, and some money in savings accounts. When these people are diagnosed with cancer, they usually have no financial problems initially; however, as time goes on and cancer treatments continue, they may lose their jobs and their health insurance, yet they are not able to access the same programs as cancer patients who were indigent when first diagnosed.
- The greatest challenge is to develop a system and programs that recognize that everyone, whether indigent or not, faces hardships when diagnosed with cancer.

MS. MARIA PARRA

Background

[Ms. Parra delivered her remarks in Spanish. She was accompanied by an English-language interpreter who translated her presentation.]

In 1997, Ms. Parra was diagnosed with breast cancer. One month prior to her diagnosis, her aunt died from breast cancer. After searching for possible alternative treatments, Ms. Parra decided to undergo a mastectomy.

Key Points

- Barriers to receiving her cancer care included language, finances, and not knowing where to go or whom to talk to about her diagnosis and treatment. She eventually found people who were able to help her get the tests she needed at no charge.
- After her mastectomy, the doctor told Ms. Parra that she was cancer-free but that she would have to take medication. Someone helped her financially so that she could continue with this treatment, but only for a short period of time, after which she had to pay for the treatment. She began working to pay for her own insurance.
- Many Hispanics in Carson City are afraid and embarrassed to see a doctor. They also do not want to travel to Reno, where most health care services are located.

Recommendations

- Health care providers should be located closer to Nevada’s Hispanic populations.
- Diagnosis and care centers should be staffed with people who speak both English and Spanish to reduce this significant barrier for Hispanics in Nevada.

DISCUSSION—STATE OF NEVADA

Key Points

- It is difficult for elected officials in Nevada to take strong stands on tobacco issues due to the libertarian nature of the State's entertainment industry, which has close ties to the tobacco industry. The Tobacco Settlement money has been appropriated, but spending it on reducing tobacco use in the State has proven a difficult concept to sell. Only 50 percent of this money was earmarked for health care, and none was used for prevention.
- Suggested mechanisms for disseminating guidelines for community tobacco prevention and control include mailings that distill the basic information, putting the guidelines on a Web site, and offering continuing medical education (CME) courses. Physicians differ as to how they integrate new information or guidelines into their practices: some do it quickly; some wait until there is a call for it; and some require an outside activity to motivate them. Constant reinforcement is key to reminding physicians that the guidelines exist, that they are useful, and that they are easily available.
- Physicians are being asked to implement these guidelines, but doing so takes additional time for which the physician is not paid, and, as discovered in HIV campaigns, many physicians are not qualified to offer appropriate counseling. HCFA (now known as the Center for Medicare and Medicaid) is about to start a demonstration project, providing Medicare reimbursement to physicians for counseling elderly patients who are Medicare beneficiaries.
- NCI funding should reflect the needs of States and local communities rather than perceived needs at the national level; communities should be asked about their research needs. NCI should notify key community groups when grants have been funded in their areas.
- Tobacco is tied to Nevada's economy and its politics, so change will be difficult to effect from within the State. Change will have to come from outside Nevada, possibly from the Federal Government. However, a significant anti-Federal mindset exists in Nevada.
- When advocates for certain diseases are successful, the resulting funding can undermine an integrated approach to care. Politicians respond to advocacy, and monies are shifted in a way that is not necessarily based on science. Universal access to health care, particularly for people with cancer, would deal effectively with the problem of categorical funding.
- Although 16 percent of Americans have no health insurance, only 7 percent of Americans who have cancer have no health insurance. This is because cancer is primarily a disease of older age and those over age 64 are covered by Medicare.
- The current structure of health coverage forces prevention into the background. If screening and preventive care were viewed as a cost-effective educational device that would more than pay for itself in saved treatment costs, these services would likely be offered more universally.

TOWN HALL FEBRUARY 1, 2001

In addition to the scheduled testimony held on February 1 and 2, 2001, the President's Cancer Panel held a Town Hall to solicit input from the public on issues and problems in obtaining cancer information and cancer care. The public was invited to attend the Town Hall to raise questions and share personal experiences. Dr. Harold Freeman, Chair, and Dr. Dennis Slamon represented the Panel. Also present were Dr. Peter Jones, Dr. Jon Kerner, and Dr. Derek Raghavan.

OPENING REMARKS

Dr. Freeman welcomed the Panel and described the purpose of the Town Hall as part of the Panel's series of regional meetings.

Key Points

JUDY ROGERS, BERKELEY, CALIFORNIA

- Ms. Rogers discussed the importance of educating all women about the limitations of mammograms. Women should realize that no test is 100 percent accurate, and manual exams are important. Because of Ms. Rogers' personal experience, in which mammography failed to detect her tumor, the mammogram report at Alta Bates Hospital (Berkeley, CA) now contains a disclaimer that reads: "Mammography does *not* detect all breast cancers." She urged that this language be adopted throughout the country.

Education about mammograms is needed for women with physical disabilities. Most older mammography machines cannot be adjusted low enough to accommodate a person in a seated position, and results are less accurate. Some treatments have been withheld from women with disabilities because of lack of both knowledge and information; for example, one woman was told she needed a mastectomy not because of the size of her tumor but because of her inability to lie still enough for radiation treatment. Unless health care providers are aware of how cancer treatment and disability interact, other problems will arise secondary to the cancer treatment itself.

TERRY SHEPARD, HUNTINGTON BEACH, CALIFORNIA

- Ms. Shepard is a special education teacher. Children with cancer are being underserved by a system that does not help parents find the best protocol, hospital, or doctor to treat the child's disease. Doctors should have a central information system so they can guide parents to the best treatment plan. (Ms. Shepard's son's doctor treated the boy for a stress fracture when he had a malignant tumor in his leg.) Doctors should be held accountable in the same way teachers are held accountable for their students' reading scores. Doctors also need sensitivity training in dealing with children with cancer and with their parents.

VIRGINIA HETRICK, PRESIDENT, YOU ARE NOT ALONE, CALIFORNIA

- You Are Not Alone provides counseling and patient education to patients with stage III and stage IV breast cancer, as well as to patients with other diseases that may be amenable to treatment using high-dose chemotherapy. Ms. Hetrick is a survivor of endometrial cancer and inflammatory breast cancer; her sister and two aunts died of metastatic breast cancer; and her mother is a 39-year survivor of endometrial cancer. She presented eight issues from the advocacy community:

- Quality of life can change, often for the better, as a direct result of patients' participation in clinical trials. For example, patients involved in clinical trials using high-dose chemotherapy for solid tumors report an enormously improved quality of life as a result of this treatment. Preliminary data from one study show that patients returned to a substantially "normal" quality of life within about 3 months of treatment, whereas patients taking the standard cyclical treatment experience a decline in their quality of life for as long as a year.
- Inaccurate clinical trials results reporting by the media, coupled with uninformed acceptance by the medical community of media reports, results in providers disregarding treatment options that may extend patients' lives.
- Mechanisms to provide consistent information about posttreatment changes and suggestions for how to return to normal functioning are virtually nonexistent. Following an intense period of medical evaluation and treatment—lasting as long as 2 years in some cases—nearly all cancer patients are told to "go home and get on with your life," with no instructions on how to do so.
- Lack of prophylactic posttreatment options for patients, especially for those who are hormone receptor-negative and/or HER-2 overexpressors, may increase the likelihood of recurrence. Development of prophylactic protocols for certain medications that are known to be effective would be a reasonable next step.
- More standardized and formally structured "compassionate use" procedures would lead to less frustration among patients with advanced cancer.
- Public knowledge databases should provide structured information for patients.
- A considerable lack of knowledge exists among primary care practitioners about how to diagnose unusual and rare cancers.
- Lack of understanding about new treatments for cancer results in inappropriate treatment of the primary disease.

MARISA PERDOMO, SOUTH PASADENA, CALIFORNIA

- Ms. Perdomo is a physical therapist who specializes in cancer rehabilitation and lymphedema therapy. She is a three-time cancer survivor: Hodgkin's lymphoma in 1978 with a recurrence in 1980 and a diagnosis of breast cancer in 1995. Research on long-term side effects of childhood cancers, specifically Hodgkin's lymphoma and leukemia, shows that people with these diagnoses are at high risk for secondary cancers such as breast cancer, brain cancer, and different sarcomas. Patients need to be told about this risk, and doctors need to follow through with patients who had childhood cancers—an especially difficult task under HMO and PPO plans. Many long-term survivors of childhood cancers are now in their thirties or forties and are beginning to experience physical signs and symptoms from the massive radiation or the high doses of chemotherapy they received. Treatment guidelines do not exist for these patients and should be developed and made available to patients and their physicians.

DR. RAGHAVAN

- The trend by some HMOs and PPOs to refer cancer patients away from oncologists once they are "cured" is a fundamentally flawed concept. Patients have been receiving cancer drugs for only 20 years, and many childhood cancer survivors are now entering the maximum-risk periods for heart disease, lung disease, and second cancers. Patient advocacy groups should join with physician groups to halt this trend.

DOROTHY BOGGES, CALIFORNIA

- Ms. Bogges has undergone two surgeries for breast cancer. Regardless of their age, breast cancer patients should be eligible for Medicare; their quality of life would be improved by severing the connection between insurance and employment.

STEVE ENGLE, DIRECTOR OF CANCER SERVICES, WHITE MEMORIAL MEDICAL CENTER, EAST LOS ANGELES, CALIFORNIA

- Mr. Engle's son died of osteosarcoma at age 12. When a patient is diagnosed through an early detection program and cannot access Medicare or MediCal, the fear level increases dramatically, and quality of life decreases. Streamlining the process to help patients access care more quickly would significantly increase cancer patients' quality of life. Nonprofit health institutions do not have "extra" money for community education and outreach, and there is no "extra" money for early detection and screening programs. Grants are available, but they are time-consuming and expensive to obtain. The cancer community should put together a program of funds for early detection and cancer education programs in the indigent community. Nonprofit institutions should be allowed to have a slight "profit" for use in education programs.

DR. RECTON, CALIFORNIA

- Dr. Recton was diagnosed with prostate cancer in 1989 at the age of 62. He had a partial prostatectomy and participated in a UCLA clinical trial of Proscar[®]. Although his experience with Proscar[®] has not been duplicated, the drug lengthened the doubling time of the cancer. While much excellent research is focused on curing cancer, little research is focused on controlling cancer (i.e., slowing it down). More time and concentration should be spent on finding out how to slow cancer growth since, especially in the case of prostate cancer, slowing tumor growth means that patients may not die from that cancer.

MARY DONOVAN, CALIFORNIA

- Ms. Donovan is a colon cancer survivor of 22 years whose mother and mother-in-law also had colon cancer. She described a water therapy and provided a paper on it from the Japanese Sickness Association: four glasses of water upon arising in the morning, followed by food or drink after waiting 45 minutes, and one glass of water 2 hours after each meal. The paper claims that this internal cleansing treatment is effective in curing 26 diseases, including leukemia, uterine cancer, diabetes, and eye problems.

DR. CATHLEEN CARR, WASHINGTON STATE

- Although Dr. Carr has had breast cancer, she spoke and presented a petition on behalf of prostate cancer patients in Washington to ensure that this group was heard. Dr. Carr urged the Panel to support work on the long-term effects of all cancers and cancer treatments and to do so by understanding the natural history of these diseases. She suggested that videoconferencing replace exclusionary meetings such as this one. She also urged the Panel to support monitoring of long-term quality-of-life issues. (Dr. Kerner noted that NCI established an Office of Cancer Survivorship several years ago, created specifically to provide funding for research on quality-of-life issues faced by cancer survivors.)

SEAN HUNT, CALIFORNIA

- Mr. Hunt is a 5-year leukemia survivor who received a bone marrow transplant. He is currently participating in three studies on survivors' quality of life. Studies should be available about the quality of life and concerns such as the long-term effects of high doses of steroids. Nursing schools should be supported financially because they are closing down due to lack of funds. Nurses are in short supply nationwide; they are needed to help educate the public about health issues.

DAVID SHOOP, CALIFORNIA

- Mr. Shoop is a two-time cancer survivor whose mother and sister died of cancer and whose other sister and fiancée also are cancer survivors. He thanked the Panel for hearing people's stories and noted that through the Wellness Community Support Group he attends he has heard many similar stories involving cancer patients' problems with lack of insurance and not receiving proper care.

SCOTT SHINTER, RICHLAND, WASHINGTON

- Mr. Shinter represented a group of cancer fighters from Richland, Washington. He read a short letter from one of those cancer fighters, Dennis Fitzgerald, addressed to Lance Armstrong. Mr. Fitzgerald's letter urged the reopening of the Fast Flux Test Facility (FFTF) for production of medical isotopes for the treatment of cancer; this facility has remained idle on the Hampton site in Washington State for the past 6 years. The FFTF is the Government's newest, safest, and most advanced nuclear reactor for peaceful purposes.

DR. OSCAR STREETER

- Dr. Streeter suggested that people seeking information on clinical trials should go to www.clinicaltrials.gov, a Government-sponsored Web site that is a clearing house for cancer, heart disease, diabetes, and other trials.

CAL BOOTH, CALIFORNIA

- Mr. Booth has prostate cancer and wishes to delay the start of treatment as long as possible because of concerns about treatment side effects. However, he urged the Panel to recommend the promulgation of clear guidelines for patients and physicians about the point at which treatment *must* be initiated. Although he has determined that the proton beam treatment at Loma Linda offers him the best chance for survival without serious side effects, his HMO will not allow that treatment, and he has signed over his Medicare Parts A and B to his HMO. Dr. Freeman and Dr. Raghavan noted the difficulty in distinguishing aggressive prostate cancers from indolent tumors, and suggested that increased molecular research is needed to improve diagnosis.

KAREN FARRELL

- Ms. Farrell was diagnosed with colon cancer 4 years ago and has been through the standard therapies. Two weeks ago, her HMO informed her that there was nothing else they could do for her. She asked why HMOs are allowed to stop cancer patients' treatment and why they can disallow treatment at other locations or participation in clinical trials. (Dr. Raghavan suggested that cancer patients in this situation should first ask a lawyer to look at the contract with the HMO to find out whether there are stated limitations to care. After that, cancer patients should make contact with a cancer center Social Work department or a clinical department. Dr. Carr added that such patients in the Los Angeles area

should contact the Cancer Legal Resource Center at Loyola Law School.) Dr. Slamon recommended contacting the NCI to find out about clinical trials that might be more provide more hope than third- or fourth-line traditional cancer treatments.

MICHAEL VELASQUEZ, LOS ANGELES, CALIFORNIA

- Mr. Velasquez is a second-year evening student at Loyola Law School and director of a support group for Latino children with cancer and their families, called *Padres Contra El Cáncer* (Parents Against Cancer). At Children's Hospital, 60 percent or more of the patients at any given time live in the Los Angeles Latino community. These children face not only a medical crisis, but also a social crisis—their parents have minimal education, are monolingual, and have a difficult time communicating with care providers. These parents want to provide the best care for their children but cannot do so because of lack of education and the knowledge and language skills to access available resources. There are young Latinos and Latinas who want to become empowered and to take responsibility for community education and advocacy and share that responsibility with medical providers.

AL MEISNER, CALIFORNIA

- Mr. Meisner is a 10-year cancer survivor whose father passed away from lung cancer 14 years ago, and whose mother was diagnosed with endometrial cancer within the past week. More funding for cancer research is needed. Although the number of cancer deaths each day is equivalent to the number of lives lost if five jumbo jets crashed daily, only 1 cent of every \$10 in taxes is devoted to cancer research. A major overhaul in managed care is needed so that patients, particularly seniors, are not forced to go outside that system to access needed medical treatment and care.

ROSALIE WALKER, CALIFORNIA

- Ms. Walker spoke on behalf of the caregivers of cancer patients. She suggested that the palliative care courses required for doctors and nurses be reviewed. Caregivers must understand that not every patient knows what care he or she is entitled to, so caregivers should offer and provide the appropriate care willingly and sensitively. Sensitivity courses should be mandatory and should include a multicultural element. Patients sometimes are not addressed eye-to-eye, are not touched, and are not considered part of their own care. Under these circumstances, many patients are robbed of many comforting hours in the short time they have left.

CAROLYN TAPP, CALIFORNIA

- Ms. Tapp is an 8-year breast cancer survivor and president of the Women of Color Breast Cancer Survivor Support Project. Inadequate treatment is the major problem facing women in the underserved and uninsured communities. Ms. Tapp recommended that a study of African-American women be conducted to find out why they are diagnosed with cancer at relatively young ages and why their mortality rate from cancer is so high. It appears that doctors do not communicate effectively with uninsured women about their diagnoses and prognoses. Some women attending her support group have large numbers of positive lymph nodes and are in their twenties. (Dr. Freeman acknowledged this issue and stated that all women, of whatever culture or race, need to have early treatment. Recent trials indicate that nothing distinguishes people according to race in terms of how they respond when they have the same treatment at the same stage of disease.)

EILEEN GARCIA, LOS ANGELES, CALIFORNIA

- Ms. Garcia is a breast cancer survivor. Health insurance premiums for some female cancer survivors are becoming too expensive due to their risk category. They must take out Major Risk insurance policies on which annual large premium increases are the norm. She also asked that funding and other kinds of support be increased for support groups; her experience with her own support group has made a significant and positive difference in her life. Everyone who has survived and who is relatively healthy should advocate on behalf of those who cannot, as well as for future generations.

FEBRUARY 2, 2001 OPENING REMARKS, DAY 2—DR. HAROLD FREEMAN

In opening the day's meeting, Dr. Freeman introduced the Panel, reiterated the purpose of the meeting, and previewed the day's agenda.

STATE OF HAWAII

Presenters

Dr. Virginia Pressler
Dr. Clayton Chong
Rev. Frank Chong
Ms. Kathlyn Tuakalau
Ms. Colette Kalawe

DR. VIRGINIA PRESSLER

Key Points

- Hawaii's aggregated cancer statistics are better than the national averages. For the top five cancer sites—breast, lung, prostate, colon, and rectum—Hawaii has earlier detection than in the rest of the United States. Stage-stratified survival for all five sites is higher in Hawaii, and overall survival rates are higher in Hawaii. Some of the survival statistics are dramatic.
- Hawaii's ethnic diversity is unique. Although the State shows excellent aggregated health statistics in cancer care, the disaggregated data are not as positive, and in some ethnic groups, the data are appalling.
- According to the National Cancer Database, Hawaii has better than average compliance with national consensus guidelines for cancer treatment. However, participation in clinical trials is not as good as the U.S. averages: Only 2 percent of adults in community hospitals are enrolled in clinical trials, although 56 percent of pediatric patients are enrolled in trials.
- Cancer care in Hawaii is fragmented and decentralized, making it difficult for patients and their families to receive comprehensive cancer care in a timely and convenient manner. A 3- to 4-week lag between diagnosis and initiation of treatment is not unusual, and for some cancer patients, that delay may be many months. Six or more separate visits for imaging and consultation are not unusual. In many cases, patients and families are their own navigators at a time when they most desperately need support.
- Major obstacles to care in Hawaii include the lack of a comprehensive multidisciplinary and coordinated system of care, lack of support for physicians to easily enter patients on clinical trials, uncertainty about health plan coverage for patients on clinical trials, inadequate public and professional understanding of the benefits and importance of clinical trials, and a large immigrant population that is not always covered by health insurance.

DR. CLAYTON CHONG

Background

Native Hawaiians constitute approximately one-fifth of the population in the State of Hawaii, with the majority of Native Hawaiians living on the islands of Oahu, Maui, and Hawaii.

Key Points

- Native Hawaiians have twice the number of single-family households as the general population. They have the highest drug-related arrest rate in Hawaii. The State poverty average is 6 percent, but 40 percent of Native Hawaiians live in poverty. Native Hawaiians' incomes are 15 to 20 percent below the average State income. The death rate of Native Hawaiians is nearly twice the national average.
- Despite advances in medical knowledge and equipment from 1910 to 1990, Native Hawaiians' death rates from cancer have worsened. For all other races, death rates from cancer reached a peak in the 1960s, plateaued, and then decreased.
- Lung cancer is the most significant killer of all malignancies, and Native Hawaiians of both genders have the highest lung cancer mortality rate of all ethnic groups in the State. A telephone survey of 5,000 homes indicated that the Native Hawaiian population had by far the highest smoking rate.
- Breast cancer rates have remained stable; but while they do not have the highest incidence rate, Native Hawaiians have the highest mortality from breast cancer of all ethnic groups. In a tumor registry study, investigators found that Native Hawaiians are most likely to have metastasis at the time of breast cancer diagnosis. Regarding breast cancer survival during a 5-year period, Native Hawaiians' 5-year breast cancer survival is the lowest of all ethnic groups in the State.
- A telephone survey concluded that Native Hawaiians have the highest percentage of females aged 50 or older who have not had a mammogram or breast examination during the past 2 years.
- Health is fifth on the list of values that are important to Native Hawaiians. The other four values, in order, are families, land, being correct and in a good relationship with colleagues and peers, and working in harmony with others. Belief in a god and spirituality are also important values.
- Four issues are important to improving health and cancer care for Native Hawaiians: working with this group's cultural values; assisting Native Hawaiians in working and complying with conventional health care; improving accessibility for clusters of ethnic groups that are difficult to reach; and cost.
- Through an NCI-funded community network grant, the *'Imi Hale* program seeks to increase: cancer awareness among Native Hawaiians; Native Hawaiians' accrual to and retention in clinical trials; research grants addressing cancers in Native Hawaiians; and the number of Native Hawaiian researchers, and to establish a research partnership that is respectful of cultural beliefs, practices, and customs. Dr. Chong is the Principal Investigator for this grant. *'Imi hale* means "to seek to establish an inheritance among children in a house that is comfortable for each individual to share."

REV. FRANK CHONG

Background

Rev. Chong is a 28-year survivor of metastatic nasopharyngeal cancer. His treatment, particularly the radiation therapy he received, may have resulted in a variety of health problems, including cardiovascular disease, cataracts, diabetes, and dental problems.

Among other responsibilities, he is a volunteer with the American Cancer Society and a cofounder of the Asian and Pacific Islander National Cancer Survivor Network.

The Waikiki Health Center's primary care clinic has approximately 7,500 medical encounters each year; 60 to 70 percent of these patients have no health insurance despite Hawaii's Prepaid Health Care Act, which requires employers to pay for health insurance for their employees. The Center's extensive outreach program works with the homeless, the elderly, runaway teenagers, people in the sex industry, and people with low incomes. Its outreach nurses have an additional 5,000 encounters per year while on the road; the vast majority of those encounters are with people who have little or no health insurance. The Waikiki Health Center partners with two Native Hawaiian healers in the provision of primary care services.

Key Points

- More public education about cancer is needed. Providing the public, even those who think they are well educated, with common knowledge is the biggest challenge. Knowledge of the early warning signals of cancer should be as common as knowledge of cardiopulmonary resuscitation (CPR).
- The long-term effects of radiation therapy are a concern, and more attention should be paid to the problems encountered by long-term cancer survivors.
- Publicly subsidized breast and cervical cancer programs now also cover treatment; however, as an example, just getting a homeless woman to a facility to obtain a mammogram or a Pap smear remains one of the most significant challenges for outreach workers.
- Cost and related issues are among the most significant barriers to care. Though people are encouraged to be screened for cancer, they are concerned that a diagnosis will place an unbearable financial burden on their families.
- The family unit is a powerful concept in Asian culture. Understanding the role of authority is critical to understanding how health-related and other decisions are made.
- Cancer is probably the least chronic of the fatal diseases, but it is the most fatal of the chronic diseases. Cancer is both a physical and a metaphysical experience. It forces people to deal with their mortality and to find their place in time and space and to make peace with their God.
- The differences between evidence-based treatment and complementary therapies must be reconciled, but it also must be recognized that mainstream American medicine is not reaching all the people; people continue to die from curable cancers.

MS. KATHLYN TUAKALAU

Background

In August, Ms. Tuakalau, who lives on the island of Hawaii, found a lump in her stomach. When she went off-island to Honolulu to have the stomach lump removed and her lungs drained, she was told she also had ovarian cancer. When she left her children in Hilo, she told them she would be back in 3 days; in fact, she stayed in Honolulu for 3 months for treatment and recuperation. She now has discovered that she has breast cancer and bone cancer. Her mother, who died of breast cancer, did not seek treatment and kept the cancer a secret from her children because she did not want to burden the family with the expense of treatment.

Key Points

- Key values that Ms. Tuakalau has been taught are to be strong for her children, to have the power to stay alive for the Heavenly Father, and to cherish her friends and coworkers.

- Ms. Tuakalau's coworkers held a cookie sale to pay for her insurance premiums during the 3 months she was away from work.
- Because she had health insurance, Ms. Tuakalau had to pay only \$56 of her \$10,000 medical bills. Had she been uninsured, she would have followed her mother's example and declined treatment so as not to burden her children with the expense of cancer treatment.

MS. COLETTE KALAWÉ

Background

Ms. Kalawé was diagnosed in 1992 with sinus cancer after having been treated without success for general sinus problems. She traveled alone to Honolulu to be tested after her sinus problems became so extreme that she was bleeding into her mouth.

The doctors were unsure how to remove the tumor and eventually told her that if they removed one eye and cut through the brain area in order to get inside to remove the cancer, she would have a 50 percent chance of survival. She consented to this surgery, which was successful. She then underwent 7 weeks of radiation in Honolulu.

Two years later, Ms. Kalawé felt another lump growing in her neck. After a needle biopsy found one more tumor, she scheduled her next 7-week radiation regimen so that she could fly to Honolulu in the morning, receive her radiation, and then return on a plane at noon to go to work. For 7 weeks, she kept that schedule because she could not afford to pay to stay overnight and possibly lose her job. Ms. Kalawé has been in remission for 7 years.

STATE OF HAWAII—DISCUSSION

Key Points

- The Waikiki Cancer Center mainly conducts cooperative studies, working with the Southwest Oncology Group (SWOG), the Eastern Cooperative Oncology Group (ECOG), and the National Surgical Adjuvant Breast and Bowel Project (NSABP). Some of Hawaii's unique cancer problems include eight times the average national incidence of hepatoma and high rates of biliary tract cancer. Studies are needed on high-incidence cancers. The Cancer Research Center should be conducting more research on local problems; presently, the Center collaborates only at the national level. Cultural differences between the university and the community create a barrier in the Center's relationship to the community. Cost remains an issue, and even though Hawaii offers a satisfactory insurance plan, a significant percentage of the population does not have health insurance coverage. Dr. Chong's community grant covers Native Hawaiians only; Filipinos, Chinese, and other Asians need the same kind of funding focus.
- Community-oriented research must be conducted with community participation in the research design and protocol. Without such inclusion, communities can feel like guinea pigs and will resent that role. Communities need to be compensated for participation in research, both in dollars and in long-term commitment to programs. Unless there is true community engagement, the community will be resentful of outsiders studying them and then leaving without real and concrete feedback about the research results. Long-term investments should be made in training local people in professional fields so that the researchers are part of the community and not perceived as strangers from a far-off land. In time, if the community is educated, community members will become researchers and give back to the community. That is the best way to bridge the community barrier, but it is not a short-term solution.

- NCI can help the State of Hawaii by continuing to offer funding for projects that assist the State in educating and obtaining more health care workers—doctors, nurses, social workers, public health workers, and dietitians—to improve health care.
- More local physicians are now being trained. In addition, there is an effort to create a cadre of community-based providers by recruiting children from neighboring islands and rural areas into the full spectrum of health care careers.
- Hawaii needs funding and other resources to help put together an infrastructure and system to train physicians and to provide the support and teamwork necessary for those physicians to offer comprehensive care.
- One of the reasons for Hawaii’s low uninsured rate is the Prepaid Health Care Act passed in 1973 that requires employers to provide health care coverage for employees. In the past, most of those employers provided family coverage. However, the number of uninsured Hawaiians is increasing because with increasing economic constraints, more companies are offering health insurance only to the employee and not covering the rest of the family. If employees work less than 20 hours per week, employers are not required to provide health care coverage for them, and more employers are hiring part-time workers to avoid providing coverage. Hawaii also has a large immigrant population that does not benefit from any of these policies.
- Under Hawaii’s managed Medicaid system, known as QUEST, patients are assigned or choose a primary care provider. Transportation can be a problem if the assigned provider is located on the other side of the island.
- On the island of Molokai, 80 percent of the population is on public assistance. On the island of Oahu, there are areas of high unemployment in which people have no insurance at all.
- Native Hawaiians have the worst health record of any ethnicity in the State. The most profound characteristic that separates Native Hawaiians from the rest of the population is income. Native Hawaiians have much lower average incomes than any other ethnic group in the State. The correlation between health and income is the most common denominator.
- Focus on the values of family and land rights can lead to disparity in health care, lack of early diagnosis, and lack of early treatment. These two values are of paramount importance to Native Hawaiians, and many are willing to sacrifice their well-being to maintain those primary values.
- A connection exists between poor health status and lack of education among Native Hawaiians. Access to care has a historical relationship to social injustice in Hawaii’s past that involved confiscation of land—first by the Hawaiian monarchy and then by the U.S. Government.
- Short-term needs include funding for programs that support advocates who interact with the community to improve health care. Long-term needs include funding for education programs to teach children that they can aspire to success and become successful, that they need to get a good education, that with education they will achieve, and that they can become contributing, employed members of society. Children must understand that they do not need to be unemployed (as is the fate of many of their parents), that they will have health insurance, and that they can become professionals.
- The importance of the family constellation must be recognized; an individual may delay treatment or may not even consider treatment because it would disrupt the family. In Polynesian, Island, and Asian cultures, the individual is less important than the family. In a cancer situation, that family focus can create a conflict: An individual is asked to make decisions that she or he is either not prepared or traditionally has not been asked to make outside of the family constellation. Western-style medicine tends to be aggressive, with individuals expected to make their own decisions. That style may collide

culturally with traditional Hawaiian values. Health care providers, both singly and as a group, should be sensitive in dealing with individuals within this family context.

PACIFIC TERRITORIES

Presenters

Dr. Aloiamoa Anesi
Dr. Robert Haddock
Ms. Elaine Low
Dr. Norma Ada
Ms. Lauri Ogumoro
Dr. Neal Palafox

DR. ALOIAMOA ANESI, AMERICAN SAMOA

Background

American Samoa is the southernmost part of the United States: 14 degrees south of the Equator, 2,300 miles southwest of Hawaii, and 1,600 miles northeast of New Zealand. It is a group of seven islands with a land mass of approximately 72 square miles. The population numbered almost 63,000 as of July 1999. The islands are volcanic with steep mountains, causing the population to be concentrated mainly in low-lying flatland areas. The climate is tropical: 87 degrees throughout the year, a wet season between March and December, and about 2,000 hours of sunshine each year. American Samoa is composed of many islands with differing access and egress issues—for example, one island has boat service twice a day; one island has boat service once every 3 months; and another island offers boat service twice a day on a fishing boat, but only if the weather is calm.

The population has an annual growth rate of 3.2 percent and an accrued birth rate of 27.7 (3.8 percent) per 1,000 population. Eighty-nine percent are Samoans, 2 percent Caucasian, 4 percent Tongans, and 5 percent from mixed groups. American Samoa is the largest Polynesian group in the world and is ranked third highest in the Pacific in population growth.

Cancer is the second leading cause of death in American Samoa, accounting for 14.2 percent of all deaths in the 10 years between 1990 and 2000. Cancers of the digestive system, urinary tract, and breast are the most common. In 2000, 53 patients were sent off-island for cancer care—to Hawaii, New Zealand, and the U.S. mainland.

Key Points

- The extended family system is important in everyday living. The *matais* (chiefs) handle all affairs, including how lands are used, and they also play an important role in making medical decisions such as what kind of treatment is taken and who receives it. This cultural family arrangement is important but sometimes becomes a barrier to obtaining cancer treatment.
- Most people will seek care through their local healers before they come into the hospital. Traditional medicine is accepted as part of the health care system, but because of rainforest clearing, many of the medicinal plants and their habitats are being destroyed.
- Before cars were available, everyone walked. Now that many people have cars, few people get much exercise because they are riding instead of walking.
- American Samoans love food, especially those containing fat and carbohydrates. Because of socioeconomic status, this is the only type of food the majority of the population can afford. As a consequence, overweight is prevalent, and diabetes and hypertension rates are high. Fish is eaten by many people, but the harbor is contaminated by toxic waste dumped during World War II.

- Tobacco and alcohol are both consumed by a large percentage of the population. It is not known whether recent increases in the taxes on both substances have reduced consumption.
- Squamous cell carcinoma due to sun exposure is becoming more common. This disease can be disfiguring—for example, some patients have had radical dissections of the nose.
- In the clinics, obesity, hypertension, and gout and their complications, including amputations and diabetic retinopathy, are the most commonly treated conditions. There is no pathologist or oncologist, and it is rare to have a radiologist, although the hospital does have a CT scanner and a mammogram machine that cannot be serviced. Mammograms and CT scans must be sent off-island to be read; reports are sent to local doctors who will perform a biopsy and develop a treatment plan.
- The Department of Health runs preventive health programs but also is responsible for environmental health, water quality, health planning, and education. Maternal and child health and immunization is the primary focus of the three doctors employed by the Department of Health. The only two preventive programs are the Breast and Cervical Cancer Program and, in the past year, the Prevent Tobacco Use Program.
- American Samoa has no cancer registry and no accurate statistics on cancer incidence or prevalence. One nongovernmental foundation offers financial assistance for people with cancer, and the hospital employs only one social worker. In the past year, the Pacific Islander Cancer Control Network (PICCN) was formed to survey Timorans, Tongans, and Samoans to interpret and disseminate cancer information, and to increase these groups' participation in clinical trials. There is one computer for all the medical staff, and teleconferencing is difficult due to the time differences between American Samoa and the U.S. mainland.
- The major barriers to health care are American Samoa's remote location and the cost of care, much of which must take place off-island. Dr. Anesi noted that cancer tends to have a lower priority than chronic diseases like diabetes and hypertension when it is being decided who should be sent off-island for care. This is due in part to the generally poor prognosis of cancer patients and the cost of cancer care.

Recommendations

- Funds should be made available to help offset the costs of the PICCN—to centralize it, to use the local infrastructure, and to keep the PICCN operational.
- Funds are needed to upgrade the medical facilities and support additional personnel.
- Encouraging off-island medical facilities to offer bilateral aid, similar to what is being done by the University of California at Irvine, will help ease the financial burden of cancer care.
- American Samoans need to be educated about cancer, associated risks, and the benefits of early detection. Education should attempt to reduce the stigma associated with cancer.

DR. ROBERT HADDOCK, GUAM

Background

Dr. Haddock has been Guam's epidemiologist since 1972. In 1999, he lost his sole staff support and was given the additional duty of being the Cancer Registrar of the newly established Guam Cancer Registry. The Registry has been collecting cancer incidence statistics for 2 years.

The total population of Guam in 2000 was estimated at 154,000. The median age on Guam is about 25.9, while that of the United States is 35.9. Chamorros, or native Guamanians, make up the largest ethnic

group on Guam, but they are no longer a majority in their homeland. Filipinos are the next largest ethnic group, and Caucasians, Asians, other Micronesians, and African Americans comprise the remainder of the population. In 1999, the percentage of Guamanian households with incomes below the U.S. poverty level was 20.53 percent; in the United States, it was 11.8 percent. The primary industry on Guam is tourism, and most of the tourists come from Japan.

Guam is about 30 miles long and 4 to 12 miles wide, with a total area of 212 square miles. The northern half of the island is composed of uplifted coral reefs, and the southern half consists of the remains of ancient volcanoes—a geography that has significance in the spread of communicable diseases. A high aluminum content in the southern part of the island has been associated with the highest incidence of amyotrophic lateral sclerosis (ALS) in the world.

Guam is the largest and southernmost island of the Marianas archipelago, which is one of five island groups of Micronesia. Guam lies 3,800 miles and about 8 hours of flight time from the nearest major U.S. city (Honolulu) and is located about 6,000 miles and 12 hours of flight time from Los Angeles. When offices open on Guam at 8:00 a.m., it is 12:00 noon in Honolulu, 2:00 p.m. in Los Angeles, and 5:00 p.m. in Atlanta—all on the previous day because Guam is located east of the International Date Line.

Key Points

- From 1898 until 1950, health services on Guam were provided by the U.S. military. Beginning in 1950, Guam became an unincorporated territory of the United States, and a civilian government was established. Medical services are now provided by a combination of public and private providers: one civilian hospital, one military hospital, several HMOs, and several private practices. However, the small size of the island means that many medical specialties are not well represented or are unavailable locally. Three public health centers on the island provide preventive services, and two of those centers provide limited outpatient services.
- The Guam Cancer Registry uses CanReg3, a software program developed for cancer registries by the World Health Organization (WHO). Initial data indicate that the incidence of cancer in Guam is lower than in any State except Utah. However, some cancers appear to have high incidence on Guam: nasopharyngeal cancer, a genetically linked cancer; primary liver cancer, which is associated with a high prevalence of hepatitis B antigen; and oral cancers, particularly in females.
- A questionnaire was circulated among physicians, public health nurses, and private clinic patients to solicit opinions about the most important problems associated with cancer care in Guam and possible solutions; virtually all respondents cited the need for more funds to fight cancer effectively. Consumer knowledge was noted as a problem. Some of the solutions suggested were to initiate intensive education programs similar to the HIV/AIDS campaign, to provide educational materials in appropriate languages, and to integrate cancer prevention topics into the school curriculum. Other suggestions included using a local role model, such as a prominent local person who had prostate cancer, as a spokesperson; using church groups or church bulletins to distribute cancer care information; and training ethnic community leaders as outreach workers for their communities.
- Additional suggestions for overcoming barriers to medical and cancer care in Guam include banning all public advertising of tobacco products, making adolescent hepatitis B vaccinations free and mandatory for school entrance, requiring prompt payment of providers by insurers and the government, and eliminating the Federal cap on Guam's Medicaid payments. Regarding insurance, suggestions included providing universal health insurance for everyone on the island, providing tax incentives to eliminate health insurance exclusions, establishing an independent health insurance commissioner to eliminate abuses by health insurance companies, and negotiating better health insurance coverage for government employees.

Recommendations

- Provider knowledge could be improved by offering more CME opportunities and establishing appropriate care standards for patient age groups and different cancer diagnoses. Because the turnover in physicians is high, physicians who leave Guam should be required to notify patients as to where else they can seek appropriate care. Routine cancer screening should be established as a standard of care by physicians and dentists. Telemedicine capabilities should be improved. The range of services provided at community health centers should be expanded. Attempts should be made to recruit specialists, such as a pediatric oncologist, to practice in Guam.
- Free bus passes provided for patients with medical appointments would address the issue of patients' inability to get to their appointments due to lack of transportation. Establishing facilities similar to the Ronald McDonald House in the cities to which most patients are referred also would help alleviate the problems associated with off-island medical treatment.

MS. ELAINE LOW, GUAM

Background

In cooperation with local organizations, the American Cancer Society provides cancer-related assistance to Medical Indigent Program (MIP) patients and cancer patients who are employed but underinsured. Its Patient Services Program provides medical necessities, such as off-island housing assistance, and quality-of-life services, such as support groups and rehabilitation programs. MIP is the local government's program providing medical coverage to low-income families with little or no insurance.

Key Points

- Guam's health-related problems are more severe because of a lack of access to current medical technology and the latest treatment options. Cancer care in Guam is affected by three major factors: geography, finances, and education.
- If so advised by their doctors, cancer patients from Guam may travel long distances to Hawaii, Los Angeles, or Houston to receive cancer care. If they have insurance, and their insurer approves, their coverage may include flight costs; otherwise, an airplane ticket costs at least \$1,500 per person.
- MIP currently has approximately 4,500 enrollee families, totaling more than 18,000 people. Because MIP is funded locally, its viability is dependent on government revenues and expenditures in other program areas. When money is not available, providers who care for MIP patients are not reimbursed in a timely manner; therefore, many providers, including the Cancer Institute, no longer accept MIP patients. When that occurs, laboratory tests, examinations, and treatments all must be performed at the already overcrowded public health clinics, resulting in all patients having reduced access to cancer screenings and checkups.
- Financial concerns also affect cancer patients who are employed but have inadequate insurance. These patients must pay out of pocket for at least part of the costs of expensive tests and treatments.
- Prevention is an important component of cancer control, but Guam's residents do not know enough about cancer prevention and education, which keeps patients from receiving the best care possible. Many women do not realize the importance of mammograms and Pap smears, and an even larger number of men do not realize the importance of PSA tests and testicular self-exams. Lawmakers on Guam appear not to realize the importance of education. Only 10 percent of Guam's Tobacco Settlement funds will be used for tobacco education or prevention.

- Many of the island's medical professionals believe that prevention of cancer through lifestyle intervention should be a priority. This includes education about the benefits of regular physical activity, nutritious eating, and tobacco cessation as lifestyle changes that can prevent some cancers.

Recommendations

- The local government should devise better ways of planning for medical care, especially through the MIP. If government revenues cannot be increased, initiatives should be reprioritized to help fund programs that are complementary to those of the American Cancer Society and other cancer and health-related agencies.
- The local government should partner with private organizations to upgrade the care facilities available on-island so patients do not have to receive medical care so far from home. Additional cancer professionals should be recruited by this partnership to practice on-island.
- Local and national governments should regulate insurance companies to ensure the highest standards of care for all patients.
- Federal grants such as the BCCCP should come with a stipulation that both public and private parties are required to review the program plans. This requirement would enable the community to be an integral part of the planning.
- Because cancer patients are entitled to know what resources are available to them on Guam, the government should work with private organizations to develop resource centers where educational materials about cancer and cancer treatment are available. Providing valuable resource information should no longer be the sole responsibility of physicians and select private organizations.

DR. NORMA ADA, CNMI

Background

The Commonwealth of the Northern Mariana Islands (CNMI) is located in the Western Pacific; it has been a U.S. Commonwealth since 1978. The island of Saipan is the capital island of the CNMI. South of the Mariana Islands are other islands of Micronesia, including the Republic of the Marshall Islands, which in the 1950s suffered the effects of atomic bomb testing at Bikini Atoll. The CNMI has been governed by Spain, Germany, Japan, and, after World War II, the United States. Spain's influence was lasting; some aspects of its culture, primarily the Spanish language and the Catholic religion, remain integral to the current culture.

Based on 1995 census figures, the population of the CNMI is approximately 58,000, of which 30,000 are Asian contract workers, 22,000 are indigenous, and approximately 4,000 are from other Micronesian islands. The indigenous peoples of the CNMI are called Chamorros and Carolinians. Chamorros constitute 33 percent of the population; Carolinians, who are from the other Micronesian Islands, constitute 5 percent of the population. The majority of the indigenous population works for the government and has government medical insurance coverage, private insurance coverage, or Medicaid.

Key Points

- Saipan has the only public hospital, the Commonwealth Health Center. The other inhabited islands of Tinian and Rota have health centers that provide outpatient services, but patients requiring consultations, surgeries, and hospitalizations must travel to Saipan.
- Other Micronesians from the Federated States of Micronesia, Palau, and the Marshall Islands constitute 7 percent of the population, a large segment of which works for the garment industry and is

not currently eligible for Medicaid. Asian contract workers constitute 50 percent of the population and are the majority of workers in the garment, tourism, and construction industries. Local law requires employers to pay for all medical expenses of these workers.

- Accurate cancer data are needed for statistics and planning. The only available data show that approximately 55 percent of cancer patients are women, and 44 percent of cancer patients are indigenous people.
- The 75-bed Commonwealth Health Care Center was opened in 1986. The staff includes internists, obstetricians, pediatricians, one radiologist, two surgeons, an orthopedist, and a pathologist. However, most biopsies are sent to Hawaii, resulting in a delay in diagnosis of 7 to 10 days. The Center has a mammography machine and a CT scan, but not an MRI or nuclear medicine capabilities. Using telemedicine capabilities, diagnosis of a brain tumor on a CT scan can be accomplished by sending the images to a neurosurgeon in Hawaii who, within minutes, renders an opinion by telephone.
- Referrals for cancer care are made to the Cancer Institute of Guam and Hawaii Regional Hospital. These referrals require a 7-hour plane ride costing from \$1,500 to \$2,000 per person round-trip. Cancer patients who are referred off-island sometimes do not return home for 2 or 3 months.

MS. LAURI OGUMORO, CNMI

Key Points

- Many people in CNMI are more comfortable with local traditional medicine than with mainstream medical care. Western providers are concerned that this preference delays diagnosis and treatment.
- Cultural differences abound. For example, a team from HCFA was concerned that advance directives were not being offered, but advance directives are a Western concept and are not culturally acceptable because the family—not the individual—must make such decisions. Religious beliefs may foster a fatalistic view of illness—as a punishment from God or God’s plan—or patients may believe that a miracle will happen if they pray hard enough. Providers sometimes continue aggressive treatment when comfort care is more appropriate.
- Local women are extremely uncomfortable sharing with male providers any information having to do with sexual organs.
- Land is culturally important and is viewed not as a commodity or an asset but as part of the family. However, in order to qualify for Medicaid or other social programs, people have had to give their land to their children before it was culturally appropriate to do so.
- Asian contract workers fear diagnosis because they fear losing their employment due to the financial liability that treatment may impose on their employers.
- For other Micronesians who were covered by Medicaid only from 1989 to 1998 and who moved their families to CNMI, free screening and diagnosis often are not followed by care. After diagnosis, many cancer patients from Micronesia return to their home islands to die.
- Off-island treatment is available in Honolulu and Guam, but it is costly to the government and to patients in terms of time and money. Patients and their families believe that traveling to Hawaii means better care, which perpetuates a lack of confidence in local providers. The CNMI has established a medical referral system that provides transportation for patients, escorts, and liaison offices in Guam and Hawaii, but this program is costly and is funded only through local appropriations.

- Other local problems and barriers include lack of an oncologist or oncology nurse, no cancer registry, and a high attrition rate of medical providers (the average stay is 2 to 3 years). Poor communication exists between on-island providers and off-island consultants; patients go off-island and often return without written protocols and discharge summaries.
- The only cancer prevention and screening program on-island is the Breast and Cervical Cancer Screening Program. Though funded in 1996, screening did not begin until 1998. It is available to all females, even if they are illegal or undocumented residents, but all clients must meet the specified income qualifications. Treatment following screening is not always available, however. Outreach is conducted by local women.
- After a 10-year struggle, the American Cancer Society has finally been accepted by the community. An annual patient education conference is sponsored by the First Lady of the United States; the first of these dealt with cervical cancer. Patient education conferences are the culturally sensitive way to address patient education and awareness issues.

Recommendations

- An oncology coordinator is needed to track patients and educate them about side effects of medication, what they can expect, and when to return for treatment.
- CNMI's two chemotherapy nurses need followup training and appropriate recognition from the Health Department.
- An oncology team should be established to address issues with cancer patients. It should be composed of physicians, social workers, community members, and nurses.
- A cancer registry is needed and should be coordinated through the Department of Health.
- Hospice or home care services should be established to support the extended families who are no longer able to bear the burden of caring for their loved ones who have cancer.
- Adequate measures for pain control are needed. Patients are sometimes kept in the hospital because of shortages of Duragesic[®] patches that they could use at home.
- Increased access to durable medical equipment is needed. At present, only one hospital bed and two wheelchairs are available to cancer patients.
- Medicaid should reimburse home health care. Patients currently are living in the hospital for the last months of their lives because families cannot care for them at home and they do not have access to necessary equipment.
- The Federal Government should develop comprehensive medical care guidelines for the other Micronesians living in the CNMI; local health providers sometimes can only send these people home to die.
- The local legislature should appropriate money from the Tobacco Settlement fund for tobacco prevention efforts.

DR. NEAL PALAFOX, MARSHALL ISLANDS

Key Points

- Significant health-related disparities exist between the mainland U.S. population and the various Pacific Islands. United States annual per capita spending on health is about \$4,000; CNMI spends about \$614; Guam spends about \$510; the Republic of the Marshall Islands (RMI) spends \$128; and

Chuuk spends \$92. RMI and the Republic of Palau have four times the infant mortality of the U.S. mainland, and the Federated States of Micronesia (FSM) has six times the infant mortality rate of the U.S. mainland. Infant mortality overall is about 7 per 100,000 live births; in the FSM, it is 42 per 100,000. Average lifespan on the U.S. mainland is 77 or 78 years; lifespan in the Marshall Islands is 64 years; in FSM, it is 65 years; and in the Republic of Palau, it is 67 years.

- Medical problems include malnutrition and vitamin deficiencies, a current cholera epidemic, a recent syphilis epidemic, and endemic diseases such as hepatitis B, tuberculosis, and leprosy (Hansen's disease).
- As part of the U.S. nuclear weapons testing program between 1946 and 1958, 67 nuclear devices were tested in this area, equal to 7,000 Hiroshima bombs. The people of Rongelap (one of the islands in the Marshall Islands) received a total body radiation dose of 200,000 millirems. Their lifetime chance of dying from cancer is 1 in 10, and their lifetime chance of developing any cancer is 1.4 in 10; an acceptable risk according to the EPA and other authorities is 1 in 1 million.
- Native Hawaiians and other indigenous people have the second highest cancer incidence overall and the highest mortality rate of all of the groups in Hawaii. Samoans are 10 times more likely to develop nasopharyngeal cancer, 7 times more likely to develop liver cancer, and 3 times more likely to develop stomach cancer than their counterparts in Los Angeles.
- Tobacco use is a major problem in the Pacific Territories, where tobacco labeling rules are different from those on the mainland. Until 1995, American tobacco companies were selling packages that did not contain any warning labels. In 1994, 18 percent of total hospital beds in CNMI were associated with smoking-related disease. Fifty-three percent of Chuukese men smoked in the 1980s, whereas about 33 percent of U.S. men smoked during the same period.
- Cervical cancer rates are extremely high. Breast cancer in the Pacific Territories has a significant genetic component for Native Hawaiians, other Pacific Islanders, and Polynesians.
- Cancer surveillance and datakeeping are developed to varying degrees on different islands but are still rudimentary. This system should have been put in place 50 years ago. The IOM recommended continual surveillance of RMI and surrounding islands.
- Cancer screening is problematic. Pap smears are difficult to obtain because of cultural barriers. The slides must be sent to Hawaii. If the island can pay the bills, the results are returned from Hawaii 6 to 8 months after the test. If the test is positive, no colposcopy or treatment is available locally. For breast cancer screening, the RMI has a mammography machine, but it has been sitting in a box for 2 years because there is no appropriately trained technician; most of the other Pacific Territories do not have mammography capabilities.
- Access to cancer treatment is available through a government-supported system; however, total health care funding is only \$128 per person per year.

Recommendations

- The Pacific Territories need a greater number and more efficient methods of capturing cancer-related data.
- Disparities need to be addressed to respond to the overall cancer-related problems of the Pacific Territories. Diagnostic and treatment capabilities are low; national finances are uncertain; patients present at late stages; access and information are poorly developed and delivered; surveillance is limited; environmental risks are high; and tobacco use is prevalent.

DISCUSSION—PACIFIC TERRITORIES

Key Points

- Guam could become a regional referral center for the closest island groups—particularly Yap, the Republic of Palau, and the FSM—but formal arrangements must be made to reimburse Guam for the care of these patients from outlying islands. The WHO is planning to designate Guam as a laboratory referral site for tests for dengue fever and other diseases, for which specimens would normally be sent to Australia or the United States. The WHO will pay the costs associated with those tests, but being designated a general referral center for patient care has added a significant burden to Guam's economy.
- Educational and technical assistance are needed for health planners. Program planning and implementation should include collaboration with medical private practices as well as with government entities. Followup site visits from granting agencies such as NCI and CDC would ensure that programs are implemented appropriately and that they remain in existence. Viability and sustainability of grant-funded efforts is key.
- Those providing technical assistance cannot hope to grasp the local situation and provide useful assistance unless they stay on site for a period of at least months—not days or weeks.
- The stark disparity in health care in the Pacific Territories is glaringly apparent on the island of Ebeye. It is a military base with golf courses, swimming pools, and a modern hospital. By contrast, the local population that works on the island has access only to a clinic that lacks equipment, medicine, and even running water.
- CNMI's Commonwealth Health Center is the only public health hospital in the Pacific Territories, and it is the only health care setting where surgeons are located and at which no one is denied treatment. The Commonwealth Health Center would make an ideal location to centralize data for the Pacific Territories.
- The Pacific Islands Health Officers Association (PIHOA) meets at least annually to exchange information, especially about dengue fever, malaria, and tuberculosis. PIHOA could be asked to collaborate and coordinate cancer statistics throughout the Pacific Territories.
- Because of the small populations on these islands, it will take time (possibly 5 or 6 years) for cancer registries to generate meaningful data. At the same time that data are being collected, education, prevention, diagnosis, and treatment options should be pursued; not to do so would hold back progress in addressing the cancer problem that is already significant in these territories.
- Differences in cancer diagnosis and treatment in Hawaii compared to the Pacific Territories can be traced to greater availability of funds in Hawaii due to its statehood and stronger infrastructure.
- The Breast and Cervical Cancer Screening Program at the Commonwealth Health Center in the CNMI has uncovered a high incidence of cervical cancer; its cause is unknown. Liver cancer also is common because of the prevalence of hepatitis B infection. In the Marshall Islands, the cancer mortality rate is high in large measure due to very late presentation of disease.
- Connections between the atomic tests and cancers have not been established publicly. Although some research has been conducted, results of those studies—and even the radiation dose and number of islands exposed to the tests—remain secret.
- Under the current system, data collection is necessary prior to receiving funding for cancer diagnosis and treatment. Research funds could be used to collect relevant data in the Pacific Territories as

effectively as a Government-funded registry specifically for health data collection. Creative avenues should be sought to collect the necessary cancer data as quickly and efficiently as possible.

- Residents of the Pacific Territories are afraid of dying from cancer and therefore are motivated to make appropriate lifestyle changes at the primary prevention level. Educational support is needed to focus on primary prevention. Consensus guidelines and funding to support translating English-language materials into Chamorro, Carolinian, and the different Asian languages would be helpful.
- The Pacific Territories need technical and other assistance in data gathering. Affiliation with one of the cancer centers on the U.S. West Coast could establish a useful partnership.

REMARKS—DR. STEVEN ASCH, WEST LOS ANGELES VETERANS ADMINISTRATION MEDICAL CENTER AND RAND CORPORATION, AND DR. JENNIFER MALIN, UCLA DEPARTMENT OF MEDICINE AND RAND CORPORATION

Key Points—Dr. Asch

- While the science and technology of cancer care have advanced rapidly in the past few years, only about half of the population has benefited from those advances.
- Quality in health care is defined by the IOM as having three elements: health services, outcomes measured by improvements in patient health, and current professional knowledge.
- Actions taken by providers can be judged by the IOM's three categories of poor care: too little care/underuse (failure to provide an effective service when a favorable outcome would have occurred); too much care/overuse (the provision of care when the risks or harm exceed the potential benefit); and wrong care/misuse (when avoidable complications of appropriate care occur).
- An example of underuse in cancer care: Randomized controlled trials and the Oxford meta-analysis have shown that tamoxifen improves breast cancer patient survival by about one-third, yet studies have shown that over one-third of eligible patients do not receive it.
- An example of overuse in cancer care: The American Society of Clinical Oncologists' guidelines recommend against giving growth factors in afebrile neutropenia. Randomized controlled trials have shown no survival benefit from this treatment, and its administration is expensive and fraught with side effects. However, surveys show that 30 percent of clinicians either sometimes, usually, or always prescribe this potentially harmful therapy in this circumstance.
- An example of misuse in cancer care: Case reports confirm the presence of misuse in the administration of cancer chemotherapy. One study identified 14 fatalities due to medication errors, including intrathecal injection of the wrong chemotherapy drug, intravenous overdoses, and intrathecal overdoses.

Key Points—Dr. Malin

- Data from the early 1990s indicate that rates of breast-conserving surgery are related to whether a hospital is a university hospital or a community hospital and, especially, to the availability of radiation therapy. However, even controlling for those important system factors, studies found widespread variations as to which women received this procedure. These variations persist despite the fact that randomized controlled trials in the early 1980s showed that the outcomes for breast-conserving surgery and mastectomy were equivalent.

- Similarly, there is widespread underuse of ovarian cancer treatment that was tested through randomized controlled trials and found to improve patient outcome. A key study showed that only 9 percent of women with stage I ovarian cancer received treatment that was consistent with the guidelines recommended by the Gynecological Oncology Association. Only 14 percent of patients with stage II and about half of patients with stage III and stage IV ovarian cancer received appropriate treatment.
- Quality of care has been shown to vary across regions of the United States. A study of survival data for early cancer in non-Hispanic Caucasian patients under age 70 indicated a nearly twofold difference in survival for patients with early-stage lung cancer, colon cancer, breast cancer, and prostate cancer, depending on where in the United States they lived.
- Procedure volume (i.e., how many of a given procedure a hospital performs) has been strongly linked to patient outcomes in some circumstances. For pancreatectomy, esophagectomy, pneumonectomy, and hepatic resection, hospitals that perform more procedures have been found to have significantly lower post-surgical death rates than hospitals that perform only a few such procedures. More research is needed to understand what underlies this association.
- Race of the patient is also associated with variations in patient outcomes. For early-stage cancer, the 5-year survival rates for African-American patients with lung, colorectal, and breast cancers are much worse than those of Caucasian patients. Socioeconomic status explains some, but not all, of the observed differences.
- Few data have been collected on the causes and effects of overuse and misuse. Based on data from studies of other diseases, overuse and misuse are suspected to be widespread problems in cancer care.
- The quality of cancer care can be measured. Widespread evidence indicates that social and system factors that can be improved are predictive of the quality of care. Further understanding is needed about these and other factors that would allow cancer care to be improved.
- The new phase in cancer research needs to be a focus on phase V studies—studies on the quality of cancer care.

DISCUSSION—DRS. ASCH AND MALIN

Key Points

- The studies of mastectomy and breast-conserving surgery have used claims data, registry data, and other administrative data sources. These sources report only what patients actually received, not the details of what they were offered or what kind of discussion took place. Studies that collect data directly from patients and from their medical records will provide an important level of detail.
- Underuse can be due to one of three general categories: lack of access, provision of wrong treatment, or lack of patient adherence. Research is needed into the causes of underuse because policy remedies are different for each category.
- For some of the quality questions, obtaining information directly from patients is crucial—whether their preferences were taken into account and whether they were presented with adequate information to make a treatment decision. This information will be especially useful in evaluating the quality of treatment for prostate, colorectal, and breast cancers.

STATE OF WASHINGTON

Presenters

Ms. Pama Joyner
Ms. Linda Jackson
Ms. Joan Ramos
Ms. Leona Miller
Ms. Betty Johanna
Mr. Joe Jay Pinkham

MS. PAMA JOYNER

Background

Washington's vision for its Breast and Cervical Health Program (BCHP) is for it to become an integrated component of the larger health care system that provides seamless service delivery. The BCHP's mission is to provide community education and services that reduce breast and cervical cancer morbidity and mortality.

Approximately 2.5 million women make up 55 percent of the Washington State population. According to Year 2000 population forecast data, nearly 90 percent of these women are white, 6 percent are Asian/Pacific Islander, 3 percent are African-American, 2 percent are Native American, and 7 percent are Hispanic. The largest minority racial group is Asian/Pacific Islanders at 6 percent, compared to 3 percent nationwide. African Americans comprise 3.1 percent of Washington's population, compared to 12 percent nationwide, and 2 percent of Washingtonians identify themselves as American Indian or Alaska Native, compared to less than 1 percent nationwide.

Key Points

- The proportion of minority women screened by the BCHP clinic is equal to or greater than the proportion of most of those women in the State, likely due to the strong emphasis on outreach to traditionally underserved populations.
- According to Washington's 1999 Behavioral Risk Factor Surveillance Survey (BRFSS), 14 percent of the adult population lacks a regular source of primary health care. The main reasons stated for not having a usual source of medical care were no need of a doctor (45 percent) and no insurance or inability to afford insurance (22 percent). People indicating "no need" suggest that primary care is perceived more as a source of treatment than prevention.
- People living in rural areas often face provider shortages, mountain roads, and long distances; these factors together result in excessive travel to receive health care. In urban areas, traffic congestion and complex public transportation routes can be barriers to care seeking. Despite creativity, funding, and the use of social service agency volunteers, transportation for clients is still a primary concern in some geographic areas of Washington—especially for people living on the islands in Puget Sound.
- Lack of health insurance is a significant barrier to screening services. As reported by the State Office of Financial Management, an estimated 625,000 Washington residents were without health insurance coverage in 1994. When asked on the 1999 BRFSS if there was a time during the past 12 months when they needed to see a doctor but could not because of cost, 9.5 percent of respondents answered in the affirmative. In the previous year, 11.6 percent of respondents had no insurance. In some instances, women with breast or cervical concerns who were screened by the BCHP refuse rescreening services due to fear of an abnormal finding that would result in a preexisting condition.

These women choose to wait for many months, hoping they might obtain health care insurance, thus delaying early detection and treatment of cancer.

- Researchers have found that adults with no insurance are sicker and have fewer ambulatory care visits and less continuity of care than insured adults. More uninsured people are likely to be diagnosed at later stages of life-threatening disease, be hospitalized on an emergency or urgent care basis, be more seriously ill upon hospitalization, and die in the hospital.
- Key findings from the *Racial and Ethnic Discrimination in Health Care Settings* report, released in early 2001, include:
 - About 1 in 6 African Americans and almost 1 in 10 persons of color overall reported experiencing discrimination in health care settings in the past year, compared to 1 in 20 of all King County residents.
 - Among the 51 African Americans interviewed, discrimination experiences ranged from incidents of differential treatment to rude behavior and racial slurs. Many respondents told more than one story of discrimination, and the events reported occurred in 30 public and private facilities across King County. These instances of discrimination were found to have a lasting effect on respondents.
 - Consequences of ethnic and racial discrimination in health settings resulted in some respondents reporting delaying treatment due to the negative experience, and many respondents mentioned actively avoiding offending personnel and/or facilities where the incidents took place.
- Another significant barrier to screening services is the limited development and implementation of culturally and linguistically appropriate education materials, programs, and provider training. Providing outreach and early detection services in a culturally sensitive manner can improve access problems. In the 1990 census, 64,625 adults in Washington indicated that they did not speak English either well or at all. In Washington counties where migrant farmworkers have settled, Spanish-speaking health professionals are needed.
- Groups with strong cultural cohesion choose services consonant with their belief systems if the choice is available.
- Washington's BHP has implemented cultural competency training for Asian/Pacific Islander and lesbian populations. However, these trainings are attended primarily by outreach workers, not the providers who will serve clients. This is believed to be due to a failure to offer CME credits and to the logistics of the training sessions.
- Access to cancer care by minority populations is limited primarily by lack of financial resources. This limitation includes clients without health insurance or the funds to cover the cost of care, as well as medical providers who can no longer afford to provide treatment and screening services for free or at reduced rates. Fewer resources are available to support culturally and linguistically diverse materials, programs, and training to better serve diverse populations.

Recommendations

- Health care providers and support staff should be trained in cultural competency. Cultural competency should be incorporated into individual performance evaluations. CMEs should be offered for this training.
- Studies should be continued that will contribute to eliminating discrimination by routinely collecting information on race and ethnic background, monitoring and reporting differential treatment, and examining and reporting experiences of other racial and ethnic groups.

- To maximize resources at the local level, training for providers should be offered, with CME credit, at times that are convenient to their schedules.
- At the State level, technical assistance and resources should be provided that effectively reach people who are hardest to serve. Fewer restrictions on Federal funds for screening would allow more effective outreach to women who are most difficult to reach.
- At the national level, renewed dialogue about the benefits of universal health care should be initiated.

MS. LINDA JACKSON

Background

The Eastern Washington Breast and Cervical Health Program (BCHP) is part of a Federally funded program serving nine eastern Washington counties. The service area extends north along the Canadian border, east along the Idaho border, and south to the Oregon border, including Spokane, which is the largest metropolitan area between Seattle and Minneapolis. About 500,000 people live in Spokane County. To the south and the east are rich farmlands and agricultural lands, and the northern counties support primarily forestry, lumber, and an aluminum industry.

Key Points

- The BCHP requires that providers be available throughout the region to ensure access for all eligible women. Approximately 850 women were assisted in 2000. If an abnormality is identified, access to diagnosis is provided within 60 days, and if cancer is identified, access to treatment is mandated within an additional 60 days. The BCHP identifies about one cancer per month.
- As an access issue, rural pride is most prevalent in farming communities where families have lived and worked for multiple generations. When people access screening services, they are required to disclose their incomes. If people wish to avoid disclosing this information, this requirement may prevent them from taking advantage of the Program. Resistance to income disclosure is so strong that people will seek care in communities where they are not known.
- Within the farm culture, women are vital to daily operations and will procrastinate and minimize their own needs to ensure that the farm is successful. Rural residents have a strong sense of family. They believe in supporting financially whatever family members may need, and they resent outside assistance, which they consider welfare. If they cannot support themselves, they will often decline needed care.
- In rural settings, issues include the need for transportation for multiple trips to providers at different locations and the need to travel long distances to each appointment.
- Rural people are astute observers of provider motivations. If they sense that a service provider is not interested or invested in the community or in individuals in the community, they will reject the services—especially in situations in which doctors have accepted rural practices as a way to pay off medical school bills.
- Antigovernment sentiment creates another access issue. A community engagement survey of Spokane residents conducted in early 2000 indicated that 29 percent of the respondents distrust the State government, and a larger percentage distrust county and city governments. Rural residents want and expect respect for their privacy; they do not want to sign papers, disclose income, or do anything that could connect them with government even if the government is offering lifesaving services.

- If women are not receiving cancer care, providers must be aware that intimate partner violence is a possible reason. Data reflect that at least 1.5 million U.S. women are physically assaulted every year; in Spokane County, 37 percent of residents report that they have experienced some form of intimate partner violence. Victims of partner violence experience manipulation and control by their abusers that manifest in such health-related behaviors as late or sporadic access to care, restricted access to routine or emergency medical care, noncompliance with treatment regimens, lack of independent transportation, lack of access to finances, restricted access to telephone communication, and reluctance of a patient to speak in front of or disagree with the partner. Abusing partners sometimes accompany the patient, remaining close by and answering all questions. These signs are even more significant when they occur in combination. Providers need to be alert to indicators of partner abuse.
- Ms. Jackson cited cases in which: partners refused to allow patients to sign forms that would enable them to receive medical assistance for cancer treatment; a spouse refused to allow his wife to be treated for breast cancer because he did not want her to be disfigured; and another spouse forced his wife to go without cancer treatment because he did not want to spend any of his retirement savings on her care.

Recommendations

- Providers must be aware of relevant issues and be willing to act accordingly, respect and respond to patients' needs, and be sensitive to each client's situation. They may not always succeed, but providers must do what they can to help patients and must document cases carefully.

MS. JOAN RAMOS

Background

Ms. Ramos is a hematologic cancer survivor who was diagnosed with non-Hodgkin's lymphoma about 5 years ago. She has health insurance and access to treatment centers. She lost her job after her first round of chemotherapy. Although Ms. Ramos considered herself to be fairly well informed, she did not understand what lymphoma was and found it difficult to obtain information about her illness. Her disease was not responsive to treatment and, with the help of her twin sister, she underwent a stem cell transplant about 2 years ago.

Ms. Ramos now works for The Max Foundation, a charitable organization dedicated to improving the odds of survival for cancer patients, targeting primarily those of Hispanic and Latin American origin. The organization is named for a young man who lost his life to leukemia when a matching bone marrow donor could not be found. Providing services in English, Spanish, and Portuguese, the Max Foundation also started the Vida Max Stem Cell Registry, which focuses on finding donors with rare haplotypes.

Key Points

- In the United States, leukemia is the single most common fatal disease among children between the ages of 1 and 15 and among adults under age 35.
- Many families are not being informed about the Federal or State programs like the Children's Health Insurance Program (CHIP), Medicaid, and State insurance plans for which they may be eligible. Some families are afraid to apply for these programs because of their immigration status, even though many States will say they do not consider the child's immigration status. In some cases, patients are told that certain services are unavailable. With intervention by an advocate, some of these decisions can be reversed.

- For families that do have health insurance, cancer treatment may still mean a tremendous financial burden.
- Clinical trials may be the only source of hope for some patients, but those patients may choose not to participate because the treatment centers may not always be forthcoming about what is and what is not covered by the patient's insurance. Ms. Ramos recounted her own case, in which she was told she was covered for the costs of her stem cell transplant, yet the week before the procedure, she was told to bring \$13,000 for the cost of a particular investigational drug. She did not have these funds and contacted her oncologist's office, where she learned that the drug cost should already have been paid to the medical center. She determined that this had indeed taken place; Ms. Ramos observed that some patients would not have known to question the situation.
- Issues that families encounter include relocation to major medical centers (often for transplants), lost wages of adult patients and adult caregivers, double housing payments at home and in treatment areas, transportation costs, prescription copays or no coverage for prescriptions, costs of over-the-counter medications and supplements that are necessary to treat side effects, lack of counseling services for family members and patients, and lack of appropriate childcare services.
- Some health plans restrict the treatment centers to which patients can be referred, although recognized and appropriate cancer specialists may be practicing at other, nonplan centers. It is not unusual for bone marrow transplants to be denied outright.
- Employment-related issues include employer exemption from the Family and Medical Leave Act (causing some cancer patients or their caregivers to lose their jobs), cancer patients not being made aware of their possible eligibility for disability pensions and Social Security Disability, and occupational and environmental hazards that may be factors in causing hematological cancers.
- Military families are provided care under the TriCare program but face similar issues—and more than those faced by the civilian population. These families, who have per capita incomes lower than the national average, often have difficulty getting referrals to specialists, and base hospitals typically lack pediatric oncologists.

Recommendations

- The National Marrow Donor Program, founded in 1987 to find unrelated donors for transplant patients, needs greater oversight.
- Funds are needed to develop and translate basic cancer education materials for adults and children. The Cancer Information Service provides an excellent service but should offer services in the dominant minority languages in each community. Currently, CIS services are available only in English and Spanish.
- Cross-national studies done in Spain, Peru, Mexico, and Southern California have found Hispanic patients to have a significantly higher incidence of a certain form of leukemia that is one of the hardest to treat. This leukemia should be studied in depth.
- People of Brazilian or Portuguese genetic descent, numbering more than 700,000 in the United States, should be included in the Federal definition of minorities. The present practice of not including these groups in minority categories affects both patients and people who wish to become health providers, as they are not eligible for minority-focused assistance programs, whether for prevention and screening, treatment, or education. The number of people of Brazilian descent in the United States is about the same as that of Vietnamese descent.

- Comprehensive services for patients and families are needed, particularly social services that bridge the information gap. The Parent Training and Information Centers, funded by the U.S. Department of Education, could provide a model for the cancer field.
- More research and funding should be devoted to complementary and alternative medicine, so cancer patients can learn which therapies may be effective and which might be dangerous. Regulation of the supplement industry is needed. Washington's legislation expanding insurance reimbursement for a broader range of providers could be adopted by other States.

MS. LEONA MILLER

Background

Ms. Miller lives on the Skokomish Reservation, where the small clinic has a Women's Wellness program. Her cancer was detected through this program. Two of her five sisters had breast cancer, with the eldest losing her life to this devastating disease. Prior to her cancer diagnosis, Ms. Miller had had several lumpectomies, all of which tested negative for cancer, and a hysterectomy.

After undergoing a double mastectomy, Ms. Miller participated in a clinical trial of two chemotherapeutic agents, which she tolerated well. She then received several rounds of radiation, during which a noncancerous mass was found in and removed from her upper arm.

In September 2000, Ms. Miller developed cellulitis and was hospitalized with 7 days of intravenous antibiotics and then released with 7 days of oral antibiotics. Because of continued swelling in her arm, she was referred for lymphedema therapy.

Although Ms. Miller has received excellent care and treatment, the expenses associated with her treatment are a continuing concern. She has no medical coverage and has had difficulty in acquiring financial assistance for medical expenses, especially the various specialized garments and bandages that she must use daily and replace regularly to control her lymphedema.

Recommendations

- Funding levels should be maintained and even increased for programs like the Women's Wellness Center and cancer treatment centers. Early detection and treatment is vital.
- Insurance companies should not be allowed to dictate where cancer treatment centers get their chemotherapeutic agents.
- More awareness is needed in the medical field regarding lymphedema and lymphedema therapy. Medical schools should make curriculum changes to include more in-depth study of the lymphatic system.
- Although the Women's Health Act of 1998 was signed into law, HCFA has not yet implemented the provisions to treat lymphedema or cover the costs of garments necessary to treat this condition. Lymphedema is a serious condition that is costly to patients.
- Therapists who treat lymphedema should be required to be certified and to complete proper training for this condition.

MS. BETTY JOHANNA

Background

Ms. Johanna had been a cigarette smoker for 35 years. In May 1999, less than a week after white spots on her tongue were diagnosed as cancerous, one-fifth of her tongue was removed. Her surgeon discovered that the cancer had spread to her neck, and Ms. Johanna underwent a second surgery in November 1999. She also received chemotherapy and radiation therapy.

During a 10-week period, Ms. Johanna endured regular chemotherapy, intravenous therapy to protect her salivary glands, radiation, a stomach feeding tube, severe vomiting, a raging systemic infection due to the feeding tube, emergency removal of the feeding tube because of the likelihood of another infection, 2 months of living on Ensure[®] only, a ravaged mouth, rapid weight loss of 65 pounds, a lung blood clot, and two hospitalizations, each a week long. About a year later, she developed a second blood clot and is now taking a drug that costs up to \$2,000 per month. Side effects from her medications have kept Ms. Johanna from sleeping well at night for the past 13 months.

Key Points

- The CDC has designated “women who partner with women” as a target group because they are less likely to seek health care in general; are less likely to visit a doctor for obstetric or gynecologic services such as birth control and therefore less likely to receive mammograms and Pap smears; are at higher risk for breast, cervical, and ovarian cancers; are affected by women’s lower earning power; and usually do not have the benefit of a spouse’s health insurance coverage.
- As long as it is legally and morally possible to discriminate on the basis of sexual orientation, access to the best medical care will be an issue for lesbians, gays, bisexuals, and transgendered individuals. Ms. Johanna noted that “When you have had your life turned upside-down by a cancer diagnosis, you should not have to worry if your health care provider would prefer you burn in Hell.”
- Twenty percent of all deaths in Washington State are related to tobacco use. However much money is spent on antismoking messages and tobacco cessation efforts, that total still is significantly lower than the costs associated with cancer treatment. Washington State collects \$252 million a year in tobacco taxes; however, \$1.5 billion is spent on direct health care costs resulting from tobacco use.
- Lymphedema is considered a lifelong condition. It is estimated that 90 percent of cancer survivors have lymphedema, although few survivors are informed about the possibility of this condition. No hospital in Seattle has a lymphedema clinic.

Recommendations

- Acupuncture clinics can be very helpful for cancer survivors who need to quit smoking. Funding for these clinics should be continued, and they should be culturally sensitive and cost-free.
- The lymphatic system needs to receive more attention in medical schools so doctors will be able to diagnose lymphedema. Insurance carriers should treat lymphedema as a chronic disease, similar to arthritis and diabetes.

MR. JOE JAY PINKHAM

Background

Mr. Pinkham is a cancer survivor and a Yakima tribe elder. The Yakima tribe is located in south central Washington State.

Key Points

- In the past 15 days, the Chairman of the Yakima tribe was diagnosed with cancer and died 10 days after diagnosis. When he realized there was nothing medical professionals could do for him, he left the hospital to die at home.
- Of the approximately 13,000 Yakima tribe members and those who are Yakima tribe descendants, there are 144 current cancer patients: 42 men and 102 women. Survivors of various cancers number approximately 74.
- The Yakima Tribe now has a doctor who works with tribe members who have cancer. Tribe members who are diagnosed with cancer and are not living on Yakima land usually come home to the reservation and receive care from the tribe's doctor.
- IHS doctors were not particularly helpful to the Yakima Tribe's cancer patients until members of the tribe met with the doctors; cancer care has since improved significantly. Meetings now are held monthly, and the problems of the tribe's cancer patients are discussed.
- In the future, Mr. Pinkham hopes to have speakers from the State health department come to the reservation to talk with Yakima tribe members about cancer.

DISCUSSION—STATE OF WASHINGTON

Key Points

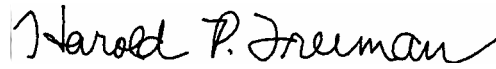
- Addressing the cultural values of pride and independence when trying to reach people with lifesaving information is a challenge faced in many parts of the country. Two approaches to dealing with this barrier are hiring clinic staff members who are known and respected within the local community and offering referrals to doctors outside of the local community to protect privacy. Outreach events should focus on the general population of women—rather than women of low income or with specific needs—to remove the stigma that may be associated with screening and assistance programs.
- Some well-established rural clinics have been successful in addressing antigovernment sentiment. People who go to those clinics have at least some level of confidence in the providers, but people who do not have confidence in the clinics or are strongly antigovernment are unlikely to seek out any health care. Outreach to these people is extremely difficult.
- People with the lowest levels of income and education live in rural and urban areas that are the most environmentally polluted and contaminated (from nearby toxic waste sites, dumps, and factories, and from pesticides contacted directly or in drinking water), resulting in exposures to likely cancer-causing pollutants. Upper income areas are seldom chosen as locations for dumps and other polluting facilities; thus, people with the lowest incomes are disproportionately affected by environmental carcinogens.
- Discrimination by medical providers against people who have different sexual orientations affects patient outcome.

CLOSING REMARKS—DR. HAROLD FREEMAN

Dr. Freeman thanked the speakers for their participation and highlighted the day's presentations. Two more regional hearings will take place, in New Mexico and in Washington, DC. In December 2001, the Panel's findings will be presented in a report to the President of the United States.

I certify that this summary of the President's Cancer Panel meeting, *Improving Cancer Care for All: Real People, Real Problems—Why Don't All Americans Get the Best Available Cancer Care?*, held February 1–2, 2001, is accurate and complete.

Certified by:



Date: 09/05/02

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