

President's Cancer Panel Meeting

Meeting Minutes

**The Real Impact of the Reduction in
Cancer Morality Research
September 29, 1997
Bethesda, Maryland**

Overview

The President's Cancer Panel was chartered to monitor and evaluate the development and execution of the National Cancer Program and to report to the President on barriers to Program implementation. The purpose of this meeting, the third in a series of four meetings focusing on the concerns of special populations in the National Cancer Program, was to review recent statistical indicators of reductions in the Nation's cancer burden, to assess how and if these reductions affect various population groups and cancer sites, and to identify key issues for research and medicine.

Eighteen speakers representing varied disciplines presented testimony to the Panel on these issues and offered specific recommendations for measures needed to extend reductions in cancer mortality to broader segments of the population, for improving data collection on specific populations to support intervention planning and surveillance of the cancer problem, and for needed research and funding in a variety of areas.

Meeting Participants

President's Cancer Panel: Harold P. Freeman, M.D., Chairman; Paul Calabresi, M.D.; Frances M. Visco, J.D.

National Cancer Institute: Richard J. Klausner, M.D., Director, NCI; Maureen O. Wilson, Ph.D., Assistant Director, NCI, Executive Secretary, President's Cancer Panel

Speakers:

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Chair, North American Brain Tumor Coalition

Phyllis Wingo, Ph.D., M.S.
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Opening Remarks

In opening the meeting, Dr. Freeman stated that:

- The final meeting in this series of four, to be held in Tampa, Florida on November 21, 1997, will examine the responsiveness of the health care system to the needs of special populations.
- Our best measures of progress against cancer in all populations have been empirical data on cancer incidence, mortality, and survival, but cancer comprises a complex number of diseases, and interpreting the data measuring reductions in cancer burden is equally complex. While mortality rates for total cancers appear to be declining in the United States, incidence rates for total cancers are increasing. These trends are not uniform across populations, however, or across disease types. Generally, the burden of cancer remains higher among minorities and other special populations such as the elderly and the poor, but this is not true for all populations or all cancers.
- The existing data raise questions as to how they should be interpreted in terms of setting research and health care priorities. In particular, unique issues exist in interpreting cancer incidence and mortality data for special populations and assessing the meaning of these data in terms of health needs of the nation as a whole. These interpretations are complicated by different methods of defining special populations, especially with regard to race and ethnicity, and can lead to differences in reported mortality rates among these populations. As we become a more multiracial society, it becomes less clear how we should classify populations in the future. Further, the status of a group as a "special populations" can vary when considering cancer as a whole compared with specific cancer sites. Important differences also exist within subgroups of defined special populations; for example, cancer incidence and mortality rates differ among Mexican, Cuban, and Puerto Rican Hispanics.
- Other factors influencing cancer rates include environmental and behavioral factors that can create geographic disparities within populations. Taken together, it is not clear what all of these factors mean in terms of the real impact in the reduction of cancer mortality, particularly for special populations.
- The increase in cancer incidence can be interpreted in different ways. Some of the increase may be due to better detection methods, outreach efforts that are achieving success in promoting early detection, or the fact that the baby-boom population is getting older and surviving longer. We need to understand the underlying reasons for the increases in cancer incidence. Although we should not diminish efforts that have led to mortality reductions, we also need to focus energies on decreasing the incidence of cancer and dealing with issues of survival after cancer treatment.

Director's Remarks

Dr. Richard Klausner, Director, NCI, indicated that:

- Cancer mortality and incidence statistics, the subject of much discussion at the NCI over the past year, are very informative, but as with all statistics, have a power that is at once mathematical, emotional, conceptual, scientific, and political. Statistics must be treated with extreme care and caution to ensure that they serve as much as possible to answer real questions about the burden of cancer. Mortality and incidence rates, while extremely important, are not the only measures of the cancer burden.
- Changes in cancer statistics are complex, and it is necessary to understand the systems that generate them to understand the numbers themselves. Recognizing the importance of this issue, a task force, to include members from NCI, the National Center for Health Statistics (NCHS), and other agencies, is being convened to evaluate our surveillance systems and the statistics they produce. The task force will be charged to assess whether the questions now being asked, the populations being monitored, and the methods of data collection and interpretation being used enable us to produce numbers that are real and useful for informing science and public policy. Dr. Klausner expressed his belief that we need a deeper and richer system of surveillance that includes a wider array of parameters, including the nature of diagnostic and detection approaches and treatment followup. It is extremely important that as cancer statistics change, we can be assured that they are reliable and that they are accompanied by a richness of information that allows us to generate sound hypotheses about the basis for observed changes in mortality, incidence, survival, treatment response and complications, and other quantifiable changes, and how these changes can be addressed.
- We must also realize that cancer statistics have a great influence on public perception of the cancer problem, and that these statistics inevitably will be used and abused.
- It is important that cancer statistics are able to answer questions posed by individuals, groups, and organizations regarding the cancer burden in particular population groups. The cancer surveillance system must also be able to identify how the burden of cancer is distributed in the population. Viewed in this manner, the burden of cancer and the true variables that are associated with altered burden themselves define the population groupings. This is not to say that individuals who self-identify for historical, political, or social reasons should not want to know how cancer affects them in terms of that identification. But we cannot assume that a social, historical, or political identification itself defines the parameters of cancer burden. Such identifications may be valuable surrogates or, alternatively, confounding or confusing surrogates.
- As we begin to understand the fundamental nature of human variability (e.g., genetic variation or genetic polymorphisms), it becomes increasingly clear that ethnicity and race are poor, if not totally inadequate, surrogates for biologic and

genetic differences. As our knowledge increases, we must beware of the potential "genetification" of race; we must not fall prey to unsound thinking purporting that race or ethnicity is biologic. There are biologic differences that relate to cancer. These polymorphisms distribute differently among different geographically derived, historically defined populations, based upon their mating patterns. But that is not the same as how an individual self-identifies, and this distinction is extremely important. The idea that race is biological is at the core of the misuse of human variation, and we must be driven to determine how the burden of cancer is distributed, so that its differing burden, rather than politics, defines the variables.

THE CANCER PICTURE

Incidence, Mortality, and Survival – An Overview

Background

The surveillance programs of the National Cancer Institute are based on the mandate contained in the 1971 National Cancer Act requiring the collection, analysis, and dissemination of all data useful in the prevention, diagnosis, and treatment of cancer. This mandate is carried out principally through the Surveillance, Epidemiology, and End Results (SEER) program that monitors the cancer burden on the population through the measurement of cancer incidence, survival, and mortality. Cancer incidence and survival data are derived from SEER's sample of approximately 14 percent of the U.S. population (with oversampling of selected populations); mortality data for the entire U.S. population are generated by the NCHS. In addition to incidence, survival, and mortality data, work is under way to develop data on cancer prevalence and the issue of multiple primary cancers.

NCI has developed a program of applied research for the assessment of individual, societal, and health services factors that mediate measures of the cancer burden both directly and indirectly. Applied surveillance research is currently exploring issues related to patterns of care, outcomes, and survivorship; the cost of cancer; health behavior and status; risk factors and susceptibility; data linkage and the use of extant data systems; and methodology and modeling studies.

Coordination, collaboration, and liaison in the development of cancer data occurs within NCI and the National Institutes of Health (NIH), with other Federal agencies and voluntary and private organizations, and with national and international consortia. Program evaluation efforts are exemplified by those assessing the impact of the ASSIST tobacco control initiative the 5-A-Day nutrition intervention, NCI's Cancer Leadership Initiatives, and usage of the Physician's Data Query (PDQ) cancer information database.

Dissemination of cancer information is carried out in large part through NCI's Office of Cancer Communications. SEER's standard data set, published annually, is also available on NCI Web sites. In addition, the first of a planned series of monographs was published a year ago.

Key Points

- SEER estimates that more than 1.2 million new cancer cases will be diagnosed in 1997. More than a half million cancer deaths are expected to occur.
- The 1970s and 1980s saw an increase in cancer mortality, with the rate of increase declining in the late 1980s. Beginning in 1990, we have seen a slow, steady decline in cancer mortality for the population as a whole. These declines are consistent for many sites and for many age groups, and are due in large part to cancer interventions and to scientific advances. These benefits have not accrued equally for all populations. In fact, the cancer burden will continue to grow because cancer now represents a larger portion of all occurring deaths; thus, it is essential that we do not become complacent.
- Despite some exceptions (e.g., increases in non-Hodgkins lymphoma, prostate, and lung cancers), overall, we are seeing an improvement in the cancer mortality profile. The extent of the decline varies by site, but declines have occurred (though not consistently) across all age groups as well as in all race/gender subpopulations (e.g., white males, white females, black males, and black females). These improvements notwithstanding, cancer incidence, mortality, and survival rates differ substantially for blacks and whites. Compared with the white population, African-Americans experience 30 percent higher incidence for some tumor sites, and lower overall survival rates.
- Lung cancer deaths continue to increase, but at a slightly slower pace. Mortality from lung cancer now represents about 28 percent of all cancer deaths. Mortality rates for men are beginning to drop, though mortality is still much higher for black males compared with white males. Lung cancer mortality for women is increasing, although cancer incidence and mortality rates overall are still substantially higher among men than women.
- Cigarette smoking is a principal cause of lung cancer. Dramatic declines in the prevalence of cigarette smoking have been achieved over the past 20 years, reflecting effective cancer control efforts. However, careful examination of the prevalence data reveals that the decline is now leveling off, and rates may actually be increasing, depending on the measurement technique used.
- Cigarette smoking levels among the teen-aged population have been relatively stable for more than 20 years. Prevalence in this population is not declining and has been the impetus for cancer control initiatives directed towards tobacco and youth.
- Data on colorectal cancer are complex. Many factors affect both incidence and mortality, such as risk due to familial predisposition, dietary habits, and survival benefits due to early detection. The data show declines in mortality among the white population, beginning as far back as the 1950s, but rates are only just starting to decline for the black population, for both men and women, with rates higher for men than for women. There is considerable variability in rates among population groups. High incidence rates are seen not only in the black population but also in such subgroups as Alaska Natives and Japanese residents in the western United States.

- Colorectal cancer has been understudied. Much research is needed to understand the various components that are linked not only to diversity in rates but also to differences in rates over time.
- Substantial differences persist in breast cancer rates for white and black women. Incidence rates are higher in white women, although mortality rates are lower and declining. Mortality rates are also declining among black females. Declines vary by decade, with greater declines in the younger population, modest declines in women aged 60 to 69 years, but no change in mortality among those aged 70 and older. Considerable variability is also seen in other populations; for example, Native Hawaiian women have among the highest rates of breast cancer.
- Many factors must be examined in interpreting breast cancer data. Trends by disease stage show dramatic increases in incidence rates for Stage O (in situ) and Stage 1 disease; these are a direct reflection of screening and early detection practices that began in the 1980s. The benefit of screening is often measured in rates for advanced disease; although some decline in rates can be seen for Stage III and IV disease, these have been relatively small. Distribution of cases by the stage of disease indicates that a larger proportion of cases are diagnosed at an advanced stage for both black and Hispanic populations. This suggests that not all populations are benefiting from early detection.
- Changes in breast cancer incidence can also be tracked by tumor size at diagnosis. Tumor size tends to be smaller in white women, although declines are occurring in diagnosis of mid-size tumors in both white and black females. These data indicate that early detection and screening are occurring in these populations.
- Survival, or outcome by stage of disease, varies among white, black, and Hispanic women. Less favorable rates for black and Hispanic populations indicate the importance of treatment and access issues.
- Although data from the National Health Interview Survey (NHIS) show that, over a 5-year period, overall rates for screening mammography have increased, particularly in the last 2 years, much remains to be understood about early detection and screening in different population groups.
- Considerable regional variation exists in radiology practice patterns and the delivery of mammography services. The Breast Cancer Surveillance Consortium is a major initiative for the 1990s, with the goal of understanding the operation and conduct of breast screening in the United States and its effect on breast cancer rates. Funding has come primarily from NCI, the Centers for Disease Control and Prevention and the Department of Defense. The Consortium fosters collaboration among researchers investigating the practice of mammography. By the year 2000, the database from nine highly diverse population sites will include over 2.3 million screening mammograms and over 24,000 breast cancer cases. The FDA will use these data to assess the quality of mammography and the performance of the nine research sites. The Consortium focused initially on defining terms (e.g., false positive, false negative), core data items, and standard guidelines for interpreting radiologic history. The group also addressed significant issues regarding confidentiality for both patients and practitioners.
- Prostate cancer data are highly controversial. Data for the mid- to late-1980s showed a rapid increase in incidence. In the last few years, however, declines in

incidence and mortality for both white and black men have been observed. The estimate of 1997 prostate cancer incidence has been revised downward from 334,500 to 209,900 expected new cases. The relationship between incidence and mortality is hard to interpret; there is currently a lack of knowledge about the factors that contribute to this decline and whether or not they are transient. Recent declines in mortality have been linked to increases in detection and screening; it is not clear, however, whether increased screening or other factors are responsible for the observed changes.

- There remains, however, a significant, twofold difference in prostate cancer mortality in black men compared with white men. Measures of disease stage also differ; distant disease is more frequently seen in the black population. It is important to note that differences in how disease stage has been defined have affected reporting. Agreement on disease stage definitions will help lead to better understanding of the data. Similarly, survival rates in the black and white populations differ in part because of the way stage mix is determined. When stage is controlled for, lower survival rates are seen for black prostate cancer patients compared with white patients.
- Because of the controversy surrounding early detection and treatment, and difficulties in interpreting available prostate cancer data, SEER initiated the Prostate Cancer Quality of Life study. This study included 33,000 white, Hispanic, and black men diagnosed in 1995 in six areas: Atlanta, Connecticut, New Mexico, Los Angeles, Seattle, and Utah. Patients have been interviewed at 6, 12, and 24 months following diagnosis. The study has attempted to characterize disease at diagnosis and to obtain information on diagnostic patterns, initial treatment, clinical sequelae, the use of secondary therapies, and, importantly, health-related quality of life throughout the 24 months. Data analysis has just begun.
- Non-Hodgkins lymphoma is a significant cancer site; both incidence and mortality rates have been increasing. Rates are higher for the white population than for the non-white population. The disease has many etiologies, ranging from viral to chemical exposures. The NCI Division of Cancer Etiology, Epidemiology, and Genetics has recently begun a major study of this significant and poorly understood cancer.
- Cervical cancer is a designated cancer control site. There are differentials in incidence and mortality, with rates substantially higher in women age 50 and older compared with younger women. Younger women are more likely to be screened for this disease. In the older population, there is great variability in incidence and subsequent mortality. High rates are seen in native populations, as well as in Hispanics and some newer immigrant population groups, especially in California.
- Recent SEER monographs present data on other important cancer sites, such as the stomach, liver, and gall bladder; these can be significant sites for some populations. The top five cancer sites differ among population groups.
- To date, SEER has not emphasized the tracking of health practices and cancer risk factors. Most of these data come from the 1987 and 1992 NHIS. SEER is working with NCHS to explore adding a cancer control supplement to the Year 2000

NHIS. Comparison of the 1987 and 1992 NHIS data on cancer control reveals several important points: (1) There has been little change in the percentage of women reporting having a Pap smear in the previous 3 years. There is an age and education gradient, and, even among older women, those women with a higher education level use this test more frequently. The test is less frequently used overall among older women, in whom cervical cancer rates are relatively high. (2) The percentage of women reporting having had a mammogram has increased, with the gradient increasing by age, and with older women having lower utilization rates compared with younger women. (3) For this 5-year period, the percentage of men who reported having had a digital rectal exam changed little. Utilization increases with age and level of education. (4) The fecal occult blood test is widely used. Utilization of this test declined in the 1992 NHIS reporting period, with differences in use linked to education. (5) Although specific questions regarding utilization of the proctoscopic exam were not included in the 1987 and 1992 NHIS, the survey reports an increase in use over the time period, with utilization differing by income level.

Discussion

Key Points

- Dr. Edwards clarified that melanoma, as one of the major cancer sites, is included in SEER reporting. The SEER data set does not include basal and squamous cell cases because these cases are often not pathologically diagnosed. There are an estimated 900,000 cases of these types diagnosed annually.
- Data can be presented in several ways (e.g., 2-, 5-, 10- or even 15-year rates). When the reporting period is long, it includes cases diagnosed in a much earlier time period; more recent data include information on more recently diagnosed cohorts. The 5-year time period chosen by SEER is used for convenience.
- The coding of cancer disease and cause of death on a death certificate, particularly when other factors are involved, is a discipline with formal rules. NCI analyzes data by the underlying cause of death.
- Several attributes of breast tumors have been measured by pathologists; however, measures of aggressiveness, such as the presence of tubules or nuclear atypia, are not routinely found in pathology reports. When these data are needed, slides are re-read by a central pathologist. Thus, some of this information is available but is not routinely collected.
- SEER is always interested in obtaining more data; for example, the program is cognizant that some populations are not well represented in terms of incidence reporting. NCI is particularly interested in collecting more information on the diagnosis path, treatment, and followup. These data are difficult to obtain, since many diagnostic workups occur outside hospital settings and may be missing from medical records. A project to explore ways to capture additional data coupled to cancer cases, such as insurance information, is under way.

- SEER files can now be linked to Medicare data on the population aged 65 years and older. Analysis of these data suggests that most of the rise in reported prostate cancer is driven by the first PSA, leading to biopsy and earlier detection.
- It was noted that while SEER data are excellent, they have limitations, and certain key geographic areas (e.g., Appalachia) are not well represented. Capturing good data on melanoma cases is difficult and resource intensive. Regarding cervical cancer, grouping data on the entire white population misses significant local area differences. For example, in Kentucky, West Virginia, Virginia, and Maine, white women have rates very similar to black women. CDC has enabled the key State cancer registries to collect data on malignant melanoma; in Kentucky, this has led to a 50 percent increase in incidence estimates for melanoma.
- SEER data on Native Americans come primarily from four Indian Health Service (IHS) areas in Arizona/New Mexico. In some ways, these data are not representative of the Native American population as a whole. The highest Arizona/New Mexico rate for breast cancer is around 11 percent compared with a national rate of 27 percent. Breast cancer data from four other Native American sites in the northern Plains area, e.g., Aberdeen, Blackfeet, Bemidji, and Nashville, differ by less than one point from the U.S. rates for all races combined. This is a major difference. As a result, research efforts may rely on data that are not representative and thus undercount the problem. In Oklahoma and California, two States with the highest proportion of Native Americans, racial misclassification is a severe impediment to effective breast cancer surveillance, exceeding 50 percent in Oklahoma and reaching an estimated 82 percent in California. Similarly, misclassification of Native Americans in the CDC-sponsored State registry databases has led to undercounting of AIDS-related deaths. Tribal leaders have made major efforts to correct errors in classification; these efforts should be supported. This problem is being addressed by both SEER and the IHS.
- Data on Hispanics for cancers other than breast cancer are available.

Additional Research Needs and Other Recommendations

- The President's Cancer Panel should support enhancement of the SEER data collection efforts and those of the CDC National Program of Cancer Registries. State registry data collection efforts should be expanded to capture treatment and followup data, as this would provide critical local-level information not presently captured through SEER.
- The SEER database should include sites from the northern Plains to improve surveillance data on American Indian populations.

Cancer in the Whole Health Context

Background

The National Center for Health Statistics (NCHS) focuses on evaluating the health status of all Americans, an activity with four principal dimensions. First, NCHS assembles data on the incidence and death rates for various diseases, together with associated morbidity. Second, NCHS evaluates the health care system in terms of how well it works; how people flow through the system; ease of access; and whether the system works differently for different types of problems or groups. Third, NCHS examines interventions that alter health, prevent disease, cure disease, or find it early. Finally, NCHS collects data on social and environmental people issues, e.g., birth patterns, family patterns, marriage and divorce rates, and how and where we live. Determining how these data relate to cancer diseases is a great research challenge.

Key Points

- The U.S. population totals 263 million. The principal minority groups represent a relatively small proportion of the total population, yet this does not mean that they are unimportant. Rather, this fraction of the population presents a challenge in terms of how NCHS resources are used to get accurate information on each and all minority groups and subgroups.
- The distribution of the four major U.S. population groups (white, black, Hispanic, and Asian American/Pacific Islander) is changing radically, both overall and within each group. Between 1990 and 1995, the Asian/Pacific Islander population grew by just over 20 percent; but between 1990 and the year 2010, this population is expected to increase by about 90 percent. The Hispanic population is expected to increase by about 80 percent overall over the same period. These enormous increases are not distributed evenly across the country. To illustrate, by the year 2015, the white population in California will become a minority.
- National data may not be useful for identifying local problems. It is a challenge to get the degree of detailed information that is needed at the local level.
- Death rates vary across different population groups. In white males, cancer accounts for about 30 percent of total deaths; heart disease accounts for about 25 to 28 percent of all mortality; and HIV and unintentional injuries account for much smaller percentages. Cancer has a somewhat different impact for each of the major population groups, though the differences are not as large as might be expected. Relative to other health problems, the mortality impact from all cancers combined is the greatest in the black population; this is true for both black females and black males.
- Heart disease is the leading cause of death for all major population groups; cancer is second; stroke and unintentional injuries or accidents are third. The leading causes of death vary for different populations: chronic obstructive pulmonary disease (COPD) among whites; HIV among blacks; and diabetes, accidents, HIV, pneumonia, and influenza for Asian American/Pacific Islanders. These

differences reflect diverse influences and factors that affect different population groups.

- Patterns of disease and related mortality typical of the home countries of rapidly growing immigrant populations (e.g., Asians) are starting to be observed in the United States. There is already evidence of this in California. We need to be cognizant of these patterns to understand the current and future health problems of the Nation.
- One way to understand the impact of cancer in the context of other causes of death is to calculate potential years of life lost due to death from this disease; the current standard approach is to calculate years of life lost up to age 75. For white males, this is estimated at about 20 percent; for black males, it is about 15 to 18 percent. Death from cancer has the greatest impact on potential years of life lost for white females at about 30 percent; for black females, the figure is about 20 percent. For females, the greatest impact on years of life lost is due to breast cancer. Disaggregated data suggest the impact of particular cancers on years of life lost and the priority with which these problems should be addressed. Importantly, however, these data do not reflect morbidity from cancer as a chronic condition, which should be considered as well.
- Socioeconomic (SES) factors, particularly education and income, play a major role in differences in cancer experience among different groups, though they do not explain all of the variation in cancer rates among different populations. Significant differences in cancer experience are observed for different categories of income (e.g., poor, near-poor, middle, high) and household status across all major population groups.
- Similarly, the rate of mammography screening, as reported in the NHIS, shows great differences in rates of utilization by category of income. However, these differences are much smaller than they were a decade ago, with much of the gap closing between 1990 and 1993. This represents a significant public health gain over a relatively short time period.
- Data on smoking prevalence from 1987 and 1994 do not show much overall difference for the various population groups; however, if SES data are factored in, different pictures emerge. For example, smoking prevalence data for 12 to 17-year-olds indicate large differences between the various populations. Black teenagers, both boys and girls, have much lower rates of smoking compared with white and Hispanic teenagers. The differences become even more striking when they are broken down in terms of SES variables, particularly income. Smoking tends to be more prevalent at lower income levels. Though important, income is only one variable affecting smoking prevalence; people with more education tend to have a lower smoking prevalence rate independent of income.
- It has been suggested that wealth, rather than income, is a better measure of socioeconomic status, particularly among older persons. Current income may be less important than the actual resources available to an individual.
- Cancer-related variables, both risk factors and actual cancers, seem to vary with respect to income and education as surrogates for socioeconomic status. It has been less clear whether the same is true for other diseases. Self-reported data for those with controlled hypertension show little difference among men regardless of

- income category, but there is a gradient with respect to income for women (i.e., a lower percentage of women with high incomes define themselves as being hypertensive than women who define themselves as being poor, although the percentage whose hypertension is controlled is approximately the same).
- Another measure of health for a country as a whole is the infant mortality rate. Overall, the United States ranks in the second decile of all of the countries in the world. Even though the infant mortality rate has been decreasing uniformly across the board, this represents a serious public health problem for the United States.
 - The dimensions of health are broad, and it is important to look at the prevalence of non-cancer health problems to adequately understand how people perceive cancer risk and the need to change or adopt behaviors that may affect cancer rates. For example, about 5 percent of persons aged 12 and older have been involved in a violent crime in some way; this rate is surprisingly stable for income level. Such concrete problems may, for instance, influence individuals' response to advice about screening for cancer or changing their diet. The total context of peoples' lives is factored into determining what is important. Moreover, in developing interventions, factors such as insurance coverage and the health care system must be considered. Understanding cancer epidemiology is valuable but is only one part of a much broader picture of health and health status.

Discussion

Key Points

- The upcoming NCHS chart book will include poverty data broken out for American Indians/Alaska Natives, who are among the poorest populations in the United States. In publishing Asian/Pacific Islander data, it is important to separate out key subgroups, particularly in terms of income. High income rates for Japanese and Chinese groups mask very high poverty rates for smaller subgroups such as the among, Native Hawaiians, Thais, and Cambodians.
- In the chart book, it will be valuable to break out smoking data for American Indians/Alaska Natives, because these groups have more elevated rates than other population groups. However, it is difficult to obtain disaggregated data on smoking habits. A Fort Collins, Colorado, researcher has gathered over 20 years of data on American Indian smoking rates. If this information could be integrated with other data sets, this would be helpful in planning interventions for these communities. Dr. Sondik noted that, currently, the NHIS only over-samples the black and Hispanic populations, which provides some data, but generally not the level of detail that is required for intervention planning. NCHS is working on ways to improve this.
- Behind each statistic are individuals, with lives and loved ones. It is predicted that by the year 2000, one in two people in America will develop cancer during their lifetimes. Cancer prevention has been a top-level objective of the National Cancer Program for many years, but since no reliable means of preventing cancer yet exists, risk factors continue to be examined to try to understand the fundamental causes of these diseases and improve the chances of intervening effectively.

- Individuals at higher income levels have a lower incidence of smoking; this has frequently been interpreted as being linked to higher educational levels (i.e., individuals with more education are better able to gather and evaluate data and may be less swayed by advertising). Although the literature also suggests that smoking prevalence is highly sensitive to cigarette price (i.e., a 10 percent increase in price would result in a 7 percent decrease in smoking), it is difficult to predict whether this would hold true for adolescent populations.
- It was noted that no data on children's cancers were presented. Many lay people are uninformed and unaware that children can and do get cancer. An estimated 2,000 children are expected to die from cancer this year alone. Education in this area is critically needed. The NCI Web site has information on incidence, mortality, and 5-year survival rates for children; the American Cancer Society (ACS) also publishes statistics on childhood cancer.
- Nearly 40 percent of all Asian Americans and Pacific Islanders reside in California; the next highest percentage reside in New York (9 percent). Other States with substantial Asian/Pacific Islander populations include Hawaii, Washington, Texas, Illinois, and New Jersey.
- For the first time, the NCHS will publish a chart book focusing on SES factors and health; this is a landmark step. However, NCHS still does not know enough about which factors are most relevant, how SES issues contribute to the generation of disease, and how this then relates to health care access and treatment. Measures are quite crude and much more research is needed.

Using Data for Cancer Control Planning

Background

Certain types of statistics are used to plan cancer control prevention programs that are sponsored by State health departments and by units and State divisions of the American Cancer Society (ACS). The data used by ACS comes from activities supported by NCI and CDC. The recent downturn in cancer mortality forces program planners to think about how to continue to make progress in cancer control efforts. ACS is using the *Healthy People 2000* (HP 2000) goals as a planning benchmark. It guides planning in four areas: reducing tobacco use in youth and adults; reducing other behaviors that increase the risk of developing cancer; increasing access to and utilization of screening procedures; and increasing access to and use of state-of-the-art, stage-appropriate treatment.

Key Points

- Cigarette smoking is a risk factor not only for lung cancer but for other cancers as well. ACS estimates that in 1997, 94,400 men and 66,000 women in the United States will die from lung cancer and that an additional 46,000 men and 34,000 women will die from the other smoking-related cancers. To make progress against cancer mortality, these numbers need to be reduced.

- About 30 percent of all cancer deaths can be attributed to tobacco use, including 87 percent of lung cancer deaths. The extent to which tobacco use contributes to death from other cancers is more variable; ranging from 8 percent for cancers of the kidney and other urinary organs in women, to 92 percent for cancers of the oral cavity and pharynx among men. These percentages also vary by race and ethnicity.
- The HP 2000 goal for adult smoking is to reduce the percentage of adults who smoke to 15 percent by the year 2000. This goal is adjusted for current smoking levels of different racial/ethnic groups (e.g., for blacks, 18 percent; Hispanics, 15 percent; American Indians and Alaska Natives, 20 percent). Currently, smoking is most prevalent among American Indian and Alaska Native populations and least prevalent among Asian/Pacific Islander men and women.
- Tobacco use data from the CDC Behavioral Risk Factor Surveillance System (BRFSS) present a picture at the State level. Only Utah has met the HP 2000 goal of 15 percent for cigarette smoking for adults. Several States are within 5 percent of the goal: Hawaii, California, Washington, Idaho, and New Jersey. The median percentage of adults who reported current smoking in 1995 was 22 percent. These data suggest that smoking control programs still have a long way to go.
- The status of tobacco use by youth is not encouraging. Research shows that lifelong tobacco addiction begins during childhood and adolescence. Between 1991 and 1995, frequent cigarette use among high school students increased by 3 to 5 percent in all racial and ethnic groups except black females. This has occurred despite intensive smoking cessation education efforts in the schools. The HP 2000 goal for this group is to reduce the percentage of young persons aged 12 to 17 years who currently smoke to 6 percent. Data from the 1995 Youth Risk Behavior Survey (YRBS) show more white youth currently smoke than either black or Hispanic youth. Smoking levels reported on the YRBS were highest among white females and lowest among black females.
- Nineteen States do not participate in the YRBS. Of the States that do report, for the variable "tobacco use by youth," all were more than 10 percent away from the HP goal of 6 percent. More than 30 percent of high school students were currently smoking in 1995.
- About 35 percent of all cancer deaths are related to nutrition. For Americans who have never used tobacco, modifying diet and physical activity habits offers the best opportunity for reducing cancer risk. In 1996, ACS revised its dietary guidelines to say: "a diet high in vegetables and fruits, low in fat, combined with physical activity, helps to achieve and maintain a health body weight." Limiting alcohol intake is also key. To affect cancer mortality, cancer control programs need to increase these kinds of behaviors in the community.
- One dietary goal is to eat five or more servings of fruit and vegetables each day; another goal is to increase to 50 percent the number of persons who eat five or more fruits and vegetables each day. Data from the 1995 BRFSS indicate that all States were more than 10 percent away from this goal. The median percentage of U.S. adults consuming five or more fruits and vegetables each day was 22, a long way from the goal of 50 percent.

- Obesity has been associated with the risk of developing several cancers, including breast cancer in postmenopausal women, endometrial cancers, and cancers of the colon and rectum. The HP goal is to reduce the percentage of adults who are obese to 20 percent. According to the 1992 BRFSS data, black females had the highest levels of obesity (38 percent); among males, Native American men had the highest level (34 percent). Alaska Native and Pacific Islander men and women had the lowest level of obesity of all racial and ethnic groups. The percentage of persons who are obese has been increasing.
- In no State surveyed in the BRFSS did the percentage of adult men who were overweight meet or fall below the 20 percent goal. The median percentage of U.S. men who were overweight in 1995 was 31 percent. Only five States are within 5 percent of the goal: Hawaii (which has a large Asian/ Pacific Islander population), Utah, Colorado, New Mexico, and Massachusetts. The data are only slightly better for women; the percentage of adult women who were overweight was at or below 20 percent in three States: Hawaii, Massachusetts, and New Jersey. The median percentage of U.S. women who were overweight in 1995 was 26 percent.
- Breast cancer is the most common cancer in women and is second only to lung cancer as the cause of cancer death in women. Early detection through mammography screening and timely treatment could result in one-third fewer deaths from breast cancer. The HP 2000 goal is for at least 60 percent of all women age 50 years and older, regardless of race or ethnicity, to have a screening mammogram every 1 to 2 years. This goal is considered achievable for all ethnic and racial groups, except possibly women of Asian and Pacific Islander origin. In this latter group, only 48 percent reported having had a mammogram in the past 2 years, 7 percentage points lower than any other racial or ethnic group.
- State comparisons on the mammography measure indicate that most States have already met, or are within 5 percentage points of, the HP 2000 goal. Only Wyoming, Louisiana, Missouri, and Pennsylvania have rates for mammography screening that are more than 5 percentage points away from the HP goal. The new ACS screening guidelines for breast cancer detection in asymptomatic women recommend annual mammography beginning at age 40.
- In 1997, 66,400 men and a similar number of women are expected to be newly diagnosed with colorectal cancers; 27,000 men and a similar number of women are expected to die from these cancers. The HP goal for colorectal screening is for least 40 percent of adults to undergo a sigmoidoscopy at some time in their lives and for 50 percent to have a fecal occult blood test every 1 to 2 years.
- According to 1992 NHIS data, a higher percentage of whites have had sigmoidoscopy and digital rectal exams (DRE) than have blacks or Hispanics. The percentage of persons who reported ever having had a fecal occult blood test was uniformly low for all three major racial and ethnic groups. The HP 2000 goal is for 40 percent of adults to have a proctoscopy at some time in their lives. Most States met the goal or were within 5 percent of the goal; the median percentage was a high 37 percent.
- Differences in access to care across racial and ethnic groups are important. Whether a family has health insurance is a key issue. The observed differences in risk factors and screening practices may in part be related to access to care and

specifically to insurance status. Of those surveyed in the 1991-1992 BRFSS, a higher percentage of men than women across all groups had no coverage by insurance, an HMO, or from Medicare or Medicaid. Native Americans and Hispanics were without health coverage more than any other racial and ethnic groups.

- Most States participating in the CDC program of cancer registries are presently collecting only incidence data and not detailed information on treatment or outcome. There is limited information in this country as to whether cancer patients are receiving stage-appropriate, state-of-the-art treatment. At the national level, neither population-based nor other baseline data are available regarding actual use of state-of-the-art treatments. To illustrate, postoperative chemotherapy is indicated for Stage 3 colon cancer patients, but anecdotal data from clinicians suggest that many of these patients are not receiving this adjuvant treatment.
- Some areas of promise include significant progress in screening for breast and colon cancers. Breast cancer mortality is declining. The percentage of women over age 50 who received mammography in the preceding 1 to 2 years was 25 percent in 1987 and has more than doubled to 56 percent by 1994. Colorectal cancer mortality is declining and the percentage of adults who have ever had a sigmoidoscopy increased from 25 percent in 1987 to 33 percent in 1992. The latest BRFSS data indicate further improvement to 37 percent. A strategy of increased screening with fecal occult blood tests and flexible sigmoidoscopy every 5 years has the potential for further significant reductions in colorectal cancer mortality.
- Tobacco use and poor nutrition continue to be areas of concern. Taken together, these factors account for more than two-thirds of cancer deaths. Smoking levels in youth increased between 1991 and 1995. Further, the Nation is getting fatter. In 1960-62, in 1970-74, and in 1976-80, about 25 percent of the population were obese, not far from the HP 2000 goal. Data for 1988-94 showed that around 35 percent of the population were obese; rather than making progress, we are losing ground in this area.

Additional Research Needs and Other Recommendations

- To achieve a long-term, continued reduction in cancer mortality, cancer control programs should put their energies into four areas, with particular attention to the needs of special populations: curbing tobacco use, particularly among youth; expanding efforts to increase screening and desirable dietary behaviors; improving access to state-of-the-art cancer treatment; and collecting surveillance data at the local level.

Discussion

Key Points

- If the HP goals are to be achieved, we need to focus on more than just racial and ethnic populations; for those with low income and educational levels it is going to

- be a long time before the HP goals can be attained for the key areas under discussion. The problems of good racial or ethnic data and the availability of data at the local level are distinct issues. It is important to remember that national data on the white population are often not relevant for poor whites in remote geographic areas (e.g., Appalachia).
- The HP goals and objectives for tobacco use include Southeast Asian males, but the nationalities included under this definition could not be specified.

THE LEADERSHIP INITIATIVES

NATIONAL Black Leadership Initiative on Cancer (NBLIC)

Background

One interpretation of the data demonstrating continuing disparate rates of cancer in our poor and minority populations is that the Nation still has a two-tiered health care system C one that serves affluent groups well, but poor and minority groups not nearly as well. The data reflect a complex web of choices in health behavior and diet, as well as greater exposure to cancer-causing agents in the workplace or the environment. One solution is the development of targeted, sustained, and comprehensive programs focused on those populations most at risk of cancer and other diseases. The NBLIC is an example of this type of outreach program. It was started by the NCI Advisory Board in 1986.

From the outset, the purpose of this initiative has been to conduct cancer outreach programs through volunteer coalitions in the Nation's African-American communities. The NBLIC is particularly concerned with reducing the high death rates in this community from breast, colorectal, and prostate cancers. The NBLIC targets the 98 percent of the Nation's African-Americans who reside in 42 States and the District of Columbia.

While NCI continues to exercise program oversight, the NBLIC's administrative office recently has been moved to the Morehouse School of Medicine, becoming an integral part of the campus community. The move is expected to bring many efforts at the School of Medicine into closer harmony, and enhance effective education for health professionals and patients about cancer prevention, early detection, and treatment.

Key Points

- The NBLIC has been able to rapidly coordinate and expand several important activities. First, an electronic information network for the exchange of relevant data has been established. This network provides for ongoing interactions between NBLIC and advocates, patients, and physicians. The network has proven to be a good forum for distributing information to the African-American community. Secondly, NBLIC is developing publications and news releases. These include educational pamphlets concerning colorectal cancer, breast cancer, prostate cancer, and the role of diet and nutrition in cancer prevention.

- The NBLIC steering committee had its first meeting in March 1997. At the meeting, the NBLIC intervention guidelines, fact sheets, and messages were formally approved. Copies were mailed to the 55 coalition chairpersons in four regions of the country in June and July. A program management document was completed in May. It provides a clear framework for how the national NBLIC office will work with its regional offices and local coalitions.
- NBLIC mobilizes African-American leaders in four regions of the country: the western region, based in Los Angeles was, until recently, chaired by Dr. Reed Tuckson at the Charles Drew University of the Health Sciences. The midwestern region is housed at the University of Illinois School of Public Health, and is chaired by Dr. Terry Mason. The eastern region is based at Harlem Hospital in New York and is chaired by Dr. Harold Freeman. The southern region (chaired by Dr. Sullivan) is based at the Morehouse School of Medicine.
- In each region, NBLIC fosters activities in cancer control, screening, media campaigns, outreach, and education. Clinical research initiatives are supported in the southern region. The regional units have been very active, increasing public knowledge of cancer prevention strategies, healthy behaviors, and healthy diets. These units also are increasing early detection efforts such as mammography and breast self-examinations (BSE), and are working to reduce exposure to environmental carcinogens. Further, they are working to increase resource referral efforts for followup diagnosis, treatment, and social support.
- Several NBLIC special events have been held. The midwestern regional staff at the Kennedy-King College on the south side of Chicago C the neighborhood with the highest incidence of cancer C held a town meeting, with more than 250 local participants. The event received extensive media coverage, thereby increasing awareness of cancer education and prevention programs, and provided an opportunity for feedback from the community. Two additional such events are planned in Chicago in the coming year - the Cancer Survivors Quilt Project and the Survivors Dinner Gala. Another regional event was Cancer Awareness Sunday, held in Louisville, Kentucky. This event was actually held on three consecutive Sundays in April 1997; it was the sixth year of such events organized by Kentucky African Americans Against Cancer, one of the NBLIC coalitions. Some 25 churches, each with more than 200 parishioners, participated in observance of Minority Cancer Awareness Week.
- The Leadership Initiative has also experienced challenges, but these have been minimized by the enthusiastic, energetic work of the regional directors, their staff, and coalition volunteers. A need for better communications within and between the regions and the national office has been identified; NBLIC has contracted with Survey Research Laboratory to help address this issue.
- NBLIC is working hard to minimize community mistrust, for such mistrust could significantly undermine program efforts. So far, communities across the Nation have embraced the Initiative, viewing it as a partner in promoting improved health status. Work with community leaders has evolved the NBLIC into a series of local initiatives active in cities around the Nation and at the State level.
- Knowledge is power in the battle against cancer, in which knowledge may be life-saving. NBLIC is important in the Nation's campaign to reduce the devastation of

cancer. NBLIC is a lifeline of information, prevention, and education efforts. This initiative is changing inner cities and rural areas, helping citizens to live longer, healthier lives.

Discussion

Key Points

- Greater funding for the NBLIC and the other Leadership Initiatives would be extremely useful.
- NBLIC recognizes the key role of community leaders in making cancer prevention and treatment information relevant at the local level. Low income individuals are greatly influenced by local leaders such as ministers or community service agency leaders and are more likely to accept information that comes from them. Involving local leadership is effective in dispelling community distrust of State or national agencies and information or recommendations coming from them.

National Hispanic Leadership Initiative on Cancer (NHLIC)

Background

The National Hispanic Leadership Initiative on Cancer (NHLIC) is similar to the other Leadership Initiatives; it is community based, research oriented, and highly focused on evaluation. The work of the NHLIC is based on social learning theory; this framework, combined with cultural sensitivity, is having a positive impact in the community.

Key Points

- The Hispanic population in the United States is growing rapidly, approaching a double-digit figure, and is quite diverse. Mexico is still the predominant country of origin for Hispanic and Latin-American populations, but even within major nationality groups there is considerable diversity.
- The Hispanic population is young compared with other U.S. populations; this may explain why cancer incidence among Hispanics is relatively low. Racial/ethnic classification issues may also complicate efforts to develop an accurate profile of the Hispanic population and its disease patterns. In addition, it has been suggested that many Hispanics, especially Mexican-Americans, may return to their country of origin for terminal care or advanced cancer treatment. If so, this can be expected to skew the data on cancer morbidity and mortality in the Hispanic population.
- It is essential to dispel the myth that most Hispanics are welfare recipients. The Latino population, although mainly poor, is very much a part of the labor force. Latinos comprise a major segment of the working poor; many are employed as

- migrant farm workers or in low-paying urban settings such as hotels and restaurants. Many Latinos lack health insurance, which creates a barrier to health care access.
- Data on Hispanics are often lacking. The NCI publication, *Rates of Risk*, 1996, does not include breakouts on Hispanics. When people consult major data sources and do not find racial and ethnic data for special populations, they may be unaware that other publications (such as the special publication on cancer risk in Hispanics referred to by Dr. Edwards) exist that could be useful. For example, NHLIC investigators and others collaborated on a little-publicized 1995 NCI monograph specifically addressing epidemiology, intervention, and diverse other issues related to Hispanics and cancer. A law is in place requiring that race and gender be considered in clinical trials; a corollary policy requiring that race and gender be part of the analysis of data at major U.S. institutions might also be in order.
 - Cancer epidemiology data show that incidence rates for Hispanics overall are lower than those for the general (white) population. Some have questioned, therefore, whether cancer is really a major issue for Hispanics. A culturally sensitive analysis of recent data on cancer and Hispanics, contained in the NCI monograph cited above, confirmed that while Hispanics' rates for certain specific cancers and for cancer overall are lower than those of the general population, their rates for stomach, liver, and gall bladder cancer are higher in both men and women. In addition, Hispanic women have high rates of cervical cancer. Subgroup variations need to be studied, particularly factors associated with rate variations at different cancer sites.
 - Often, minority populations are studied from the perspective of what is "bad" for them. It is somewhat of a paradox, given the increased cancer risk typically associated with the lower SES and education levels of many Hispanics, that Hispanics generally have lower incidence rates for cancer. What is it about this culture and these groups that account for these lower rates? This paradox exists for cardiovascular diseases and birth outcomes as well as for cancer. Despite high risk factors and the extent of poverty in the population, Hispanic incidence rates for chronic disease are lower than those for the general population. There may be protective factors at work, such as diet or certain cultural attributes; these should be explored.
 - NHLIC evaluation data on the use of mammography screening, Pap smear, and smoking cessation have shown that when coalitions develop targeted intervention, desired changes in behavior in Hispanic communities can be achieved.

Discussion

Key Points

- Puerto Ricans resident in the Commonwealth are included in the U.S. census reports. The extent to which Puerto Ricans are included as a separate group within the overall calculations for the U.S. Hispanic population is unclear.

- The definition of "Latino" (or "Hispanic") can be problematic. From a cultural point of view, these are the people who have predominantly come from Latin America, who speak Spanish. Beyond these parameters, Latinos are probably best defined on a geographic basis. For example, in San Diego, there is a melting pot that is predominantly Mexican; in other areas, Latin-American groups come together and form geographically based cultures. That type of pattern occurs in Miami where the dynamic forces of immigration in the Caribbean, political upheavals, and revolutionary situations in other countries have resulted in population influxes. What they have in common is that these groups come from Latin America and speak Spanish. After that, they are as diverse as the poor white U.S. populations. NHLIC has consciously focused on targeting those who are low income and who speak Spanish. These are the people who are missing the message from the mainstream, English-speaking mass media and standard public health programs, which do seem to reach the Hispanic middle and upper classes.

Additional Research Needs and Other Recommendations

- Program planning for the Latino population is hampered by insufficient data collection and limited staff available to collect, analyze, and formulate both programs and policy based on the data. Additional funding is needed to address these issues.
- Since the Hispanic population is concentrated geographically far from Washington, D.C. near the U.S./Mexican border Hispanics tend to be unempowered politically. Funding for SEER data collection related to cancer in the Hispanic population needs to be concentrated in the areas where the population is clustered.

Appalachian Leadership Initiative on Cancer (ALIC)

Background

Begun in 1994, the ALIC is a research program focused on the higher cancer mortality of the Appalachian population. The monograph *Sowing Seeds on the Mountain*, published by NCI in 1994, presents information concerning the social and economic history of Appalachia, health status and health care in the region, cultural characteristics of the population, theory-based information about community coalition building, and the proposed research approaches of the four projects that comprise the ALIC program. The monograph clearly shows that for the medically underserved in this predominantly rural, largely white population, the underlying problem is poverty, with "culture serving as a prism through which poverty exerts its effects on health." (Freeman)

Cancer control in Appalachia must be seen as a social problem, not just as a medical problem. Both research and program development must have a multidisciplinary and interdisciplinary base, with the involvement of sociologists, anthropologists, and other social scientists, as well as cancer experts. Within this context, the ALIC has established

three principal research questions: (1) Is there a general framework for developing and sustaining community cancer control programs in socioeconomically disadvantaged, rural communities through which specific cancer control efforts can be pursued? (2) What is the role, if any, of universities in developing sustainable, community-based cancer control programs and in developing and sustaining cancer control networks? (3) What is the role, if any, of the NCP in developing and sustaining community-based cancer control programs and in developing and sustaining cancer control networks?

Key Points

- The ALIC comprises four projects. Two are based in the cooperative extension services at Pennsylvania State University and North Carolina State University, and exemplify the private-public partnerships central to the ALIC. The other two programs, one based at the University of Kentucky, the other in West Virginia, are part of NCI cancer centers. Thus far, there are no programs based in Alabama or Mississippi. At present, there are 75 coalitions across the ALIC region, and each of these coalitions includes community-based, private-public partnerships. The population of interest is primarily rural, aging, and of low income. Interestingly, in the four ALIC projects, the non-white populations under study are predominantly urban.
- Appalachia presents many personal and systemic barriers to cancer screening, diagnosis, and treatment. These include poverty, isolation (due to geography, transportation issues, low literacy, cultural issues, and age-related factors), fear, and the availability, accessibility, and acceptability of services. Lack of continuity of care is not a new problem in the U.S. health care system, but it is a real problem in Appalachia, particularly when repeated cancer screenings are needed.
- Appalachia is a remarkable laboratory for studying those who are underserved, have relatively low education and income levels, and are predominantly white. There is little or no confounding effect of race and ethnicity. This is not to say that there is no African-American population, particularly in the Southern part of the region; however, the area of Appalachia currently served by the Initiative is about 95 percent white.
- Medical research tends to focus on the individual and strategies for effecting individual behavior change. However, the social context of individuals' lives must be taken into account, particularly when conducting cancer control research.
- In 1993 testimony to the President's Cancer Panel, Dr. Friedell stated that "if the problems are in the community, the solutions are in the community." After 5 years with the ALIC program, he is more convinced than ever that this is true. It also appears true that even as individual communities find ways to deal with their own cancer control issues, they want to connect with other communities. They value networking, and when they need help in overcoming an obstacle, they want a designated place to turn.

Additional Research Needs and Other Recommendations

- To sustain community cancer control efforts, there needs to be an enabling entity C a governmental or non-governmental agency C that can provide the encouragement, technical support, and connection with other community cancer control efforts, interstate or intrastate, and with other resources as needed.
- Continued and expanded cancer control research at the local level is needed.
- Community-focused cancer control research and implementation efforts at the Federal level should be integrated and have a high priority. At present, several agencies deal separately with similar issues.
- Goals and objectives should be set at the Federal level, and program oversight should be conducted at the Federal level. However, flexibility in implementation is important; for example, the CDC works with State health departments, which in turn are quite variable in the way they deal with community-based cancer control research efforts.
- Private-public partnerships in both research and program implementation at the community level should continue to be fostered.
- Improved cancer data collection and analysis at the State level through the continued and expanded support of the National Program of Cancer Registries and SEER is very important, and SES data are badly needed.
- Expanded collection of followup data is needed in State registries; some States are already doing this and can serve as pilot sites for others to emulate.
- Grant announcements should be developed addressing special populations other than minorities as currently defined (e.g., rural, low income, or low education), as this is where the burden of cancer lies.
- Increased coordination of the National Cancer Program is needed, at least at the Federal level. The NCP should set national goals and priorities, monitor progress towards goals, and have the capability to move the overall program forward. There must be designated leadership for the NCP, and a focal point for accountability.

Discussion

- Common to all of the Leadership Initiatives is the need to work at the community level in order to engage underserved populations in program activities. Getting the message out is not enough. A behavioral response must be engendered. This can only occur in a social context in which the community supports individual change. All of the Initiatives are working towards this goal in different ways (e.g., demonstration projects, research). The common denominator is the recognition that different populations have distinct cancer problems that must be addressed in their communities.
- All of the Leadership Initiatives deal with poor populations. A common thread that must be recognized is that those who are poor, and who are often less well educated, are not as effective in assimilating for themselves information that is widely available to the public. Frequently, these populations rely on local institutions for cues regarding their behavior; this underscores the importance of involving credible local leaders to impart information that would not be accepted

or understood from reading a monograph or from the recommendation of a national or local official. For example, women from the community have been trained as health advisors, in some areas, and have been instrumental in conveying health messages and increasing cancer screening rates in a wide variety of local programs.

- NHLIC and other Leadership Initiative minority investigators, as well as the ALIC, are developing and showcasing technologies that reach special populations. These models need to be adopted and institutionalized by major organizations, such as the ACS, so that they can be continued when the special funding used to develop them has expired.
- It was underscored that there is no "one-size-fits-all" approach to cancer control efforts at the community level. Concepts have to be modified to accommodate specific community needs.
- The emphasis over the years that poverty is a common denominator in cancer mortality statistics is valuable.
- Coordination of the large and amorphous undertaking that is the National Cancer Program has proven extremely difficult. In the early 1970s, this was the responsibility of the NCI Director. More recently, however, with many agencies now involved in cancer-related activities, this is no longer the case. The far-reaching goals of the NCP can sometimes run counter to those of the NCI, which is primarily a research organization. It was suggested that the President's Cancer Panel or an external advisory body should be charged to develop a badly needed strategic plan, goals, and methodology for monitoring progress toward those goals.
- The lack of coordination between cancer control research and cancer control implementation illustrates the overall coordination problem within the NCP. NCI is concerned with research, while the CDC, working primarily through State health departments, focuses on implementation. This approach leaves a large crack into which important activities may fall. Concern was expressed that the Leadership Initiatives, which have only 2 years of funding remaining, are at risk of such a fate. Although it is not expected that NCI will fund the Initiatives forever, it is important for the successful activities of the Initiatives to be continued. If this charge falls to the CDC, it will have to develop a culture of research in addition to its current implementation orientation. In addition, there is need for an amalgamation of effort among the Federal Government, the ACS, and other private sector organizations to adequately address the cancer control issues of special populations. Fundamentally, however, there must be agreement that there should in fact be a National Cancer Program; such a consensus is not currently evident.
- It is extremely difficult for two distinct agencies (i.e., NCI and CDC), with different charters, to share parallel leadership roles. One possible locus for coordination of the NCP is the Office of the Assistant Secretary for the Public Health Service (PHS), since established relationships exist with all of the PHS agencies; an alternative placement could be the Office of the Secretary, Department of Health and Human Services. It is difficult to impose leadership and coordination of activities on an agency at a parallel level and with parallel

- functions. Thus, placing responsibility for coordinating the NCP at a higher level may make sense.
- Cancer control needs to have a very high and visible priority; it must be placed organizationally where there is a commitment to its success, and where both research and implementation needs can be met.

Native American Initiatives

Background

Native American populations have never had a formal initiative similar to the NBLIC, NHLIC, or ALIC. Although there is strong interest in establishing an initiative to develop and implement innovative projects for Native American populations, this opportunity has been denied. Instead, the Network for Cancer Control Research Among American Indian and Alaska Native Populations has been established, but unlike the various Leadership Initiatives, which have been funded in the millions of dollars, annual funding for the Network has never exceeded \$42,000 a year. This lack of long-term support has been a major obstacle to the development of community trust and to sustaining community interventions.

The Network has published a plan detailing what is needed at the Federal level to control cancer in American Indian/Alaska Native populations. A separate strategic plan aimed at CDC-based State programs will be published in the *UCLA Journal of American Indian Issues* within the next 3 months. Three Native American conferences have been held; their proceedings have been published in peer-reviewed journals. In addition, the Network has conducted national surveys of all Federal reservations, urban Indian clinics, and State organizations, to gather information on current cancer prevention and control activities for Native Americans. Findings from these surveys have been published.

Key Points

- In 1992, the Congress passed legislation to support a Native American initiative; funds were approved, but never released. Focus groups were held to identify what was needed to address growing cancer problems in Native American communities. The need for data was identified, but more importantly, the need for special research initiatives for Native Americans, many of whom are medically underserved, was emphasized. The needs of the underserved population are related to poverty, but they also include psychosocial and sociocultural issues, as well as the need to change counterproductive policies (e.g., unavailability of breast cancer screening for women under 50 years of age).
- Whether for a Leadership Initiative or a Network, internal leadership - someone within NCI who is willing to make decisions, provide long-term direction, and be involved with the funding agency C is crucial. The Network is housed at NCI; Dr. Edwards of SEER has provided direction for support in this area and was instrumental in bringing Dr. Lillian Tom-Orme to NCI, who can speak to special Native American concerns.

- Cost-effectiveness as a grant review criterion can have negative effects on program success in hard-to-reach populations. For example, in Los Angeles, where the Native American Cancer Research Program (Pine, CO) has a screening project, there are 500 licensed mammography providers. It took 8 months to access screening for Native American women living in LA county, however, because of the cost of bringing them to the screening facility. Since the project staff could not guarantee providers a minimum number of women (e.g., 40 patients), screening for the population was deemed not cost-effective. Inconsistent access to screening erodes program credibility and trust in the community. Further, cost-effectiveness criteria tend to result in the medically underserved becoming "unserved." It is more expensive to involve them mutually (i.e., first 3 years of the project) in screening programs. Projects targeting "hard-to-reach" communities often are not funded in favor of those that can screen a higher number of underserved individuals for the same level of funding.
- There is concern in the Native American community that the National Cancer Program (e.g., Department of Defense [DoD]) places a higher priority on the needs of underserved populations overseas than on those of underserved populations living in the United States.
- NCI has, through the RO1 mechanism, funded the Native American Women's Cancer Initiative; however, funding for some of the grantees expires this year, and next year for the remainder of the awardees. It will be important to continue these efforts through another initiative. The Native American Research and Training Program, which provides training for young investigators, may provide such a vehicle. Few Native American researchers work in the cancer area; most focus on diabetes, alcohol, or HIV problems. It is important to bring Native American investigators into the cancer field, so that the growing cancer problems of the population can be addressed. Dr. Edwards has been of enormous assistance to the Network in finding resources to provide training for young Native American investigators.
- NCI supports a Network meeting every year. The Mayo Clinic supported a meeting in 1993 and will sponsor another in 1997. NCI has also provided supplemental funding to the Mayo Clinic for infrastructure development for the new Native American Resource Center to be called the "Native Circle." This Center will be in a central location and will house data collection instruments that have been modified and used successfully with Native American populations. It also will include summaries of previous research and successful service projects, educational resources, and a speakers' bureau.
- CDC has supported Native American initiatives, funding 12 tribes and an urban Indian Center. The Indian Health Service (IHS) has had a special cancer prevention and control program; however, funding for this initiative has recently been cut by 50 to 75 percent, and the agency's cancer focus has been broadened to include all chronic diseases. Further, there is speculation that the IHS may cease to exist within the next few years. To date, the Department of Defense has funded no Native American breast cancer projects. The Health Resources and Services Administration (HRSA) has expressed an interest in future Native American

- initiatives, as has the ACS, which published proceedings from the Network's cancer conference in its journal, *Cancer* (Oct 1996).
- The Agency for Health Care Policy and Research (AHCPR) conducted a survey of Native Americans in the late 1980s as part of the National Medical Expenditures Survey. Survey design and data collection effectively involved trained interviewers; however, data analysis was conducted by non-Natives and is of limited utility.
 - Support for community-based service, education, and research programs is eroding, including programs for Native Americans, largely as the result of a Federal freeze and budget cuts.
 - Cervical cancer patterns differ in Native American women compared with women of other races. In Native American women, the disease is much more aggressive and is found in younger women. The reasons for this are not known. A similar pattern for breast cancer has been observed, but insufficient data exist to support development of a hypothesis.

Additional Research Needs and Other Recommendations

- Addressing access barriers related to poverty is important, but insufficient to effectively recruit and retain medically underserved populations in state-of-the-art cancer care projects.
- Psychosocial and sociocultural interventions are needed to recruit and retain populations that hold belief systems that differ from the "majority" cultural values.
- Greater support is needed for community-based and community-driven cancer research interventions.
- Cancer survivors need greater visibility and leadership opportunities.
- A cancer registry is needed that collects data about cancer patterns in indigenous populations.
- Culturally relevant and competent interventions are needed to increase Native cancer patients' survival from cancer.
- Special initiatives are needed to ensure that Native American cancer patients have access to state-of-the-art cancer prevention and control services, interventions, clinical trials, and support services.
- Special initiatives are needed targeting medically underserved and "unserved" populations (e.g., small tribes urban clinic).
- Health care facilities should train and support culturally relevant "navigators" to facilitate patients' interactions with the health care system.
- A central clearinghouse of culturally relevant Native American cancer resources is needed (and is in its formative stages through the "Native Circle" located at Mayo Clinic).
- Medically underserved populations and cancer survivors should be included in cancer research projects in paid, rather than voluntary, positions.
- Racially specific and accurate databases are needed. Age-adjusted disease data from Federal agencies needs to be racially specific and based on the same

standard population (e.g., "1970 Std Pop" or "Yr 2000 World Pop") so that comparisons can be made.

- Cost-effectiveness as a research grant criterion should be applied only after a project has become established in the community (e.g., after 3 years).

Discussion

Key Points

- The reasons underlying disparate cancer rates among minority groups (e.g., lower cancer incidence rates among Hispanics) should be an important focus of the Panel.
- The Department of Defense Web site contains information on the proportion of DOD funds allocated to minority issues, which remains comparatively "small"; a committee provides continual oversight to ensure that proposals are funded according to both merit and need.
- Racial misclassification is a significant issue in attempts to determine cancer rates for Native American groups. Rates are highly diverse in different parts of the country (e.g., in the northern Plains tribes, rates for lung and breast cancer are very high compared with other Native population groups and other racial groups). Rates for colorectal cancer in Alaska Natives are puzzling, and within that population vary substantially for Aleut, Athabaskan, and Eskimo subgroups. Very limited data are available for these populations and are not well understood. Survival percentages for childhood cancers for Native Americans/Alaska Natives are the lowest for any racial or ethnic group.
- Parents and families of children diagnosed with cancer shoulder a heavy burden of care. With the advent of managed care, it is especially important to link those families with all available services and with each other.
- The ALIC is presently conducting both process and outcome evaluations. Findings will be available for review by the research community to determine effectiveness. Research output from the projects will justify the importance of funding these initiatives.
- For the NBLIC, evaluation will measure changes in behavior, using such variables as the percentage of women who do breast self-examination or have mammograms and the percentage of men who have had a digital rectal examination (DRE) or a fecal occult examination within the past year. Through linkages with the 5-A-Day program, the NBLIC will measure the percentage of the target population who are consuming five servings of fruit and vegetables a day. Levels of awareness about cancer and cancer screening are being studied.
- In contrast to much of the research typically funded by NCI, the Leadership Initiatives have discovered that it takes several years to establish projects and have some degree of organization in place in the various participating communities.
- The Hispanic and Native American populations are each comprised of a number of distinct cultures; these subgroups need to be accessed through culturally

- appropriate cancer control messages. This suggests that funding smaller, more focused initiatives may be more effective than larger efforts. At the same time, there are many benefits associated with working as a group. The Leadership Initiatives enable investigators to share resources, models, and strategies; in addition, investigators develop a valuable, shared perspective they would not have obtained working in isolation.
- Subgroup variation can be evaluated when a unified protocol regarding knowledge, attitudes and behaviors, as these relate to interventions, is used to compare distinct groups (e.g. Cuban-Americans in Miami, Mexican-Americans in the San Diego area). When this approach is used, variations in different groups emerge and distinct, geographically based problems are seen. This approach is not being used on a national level to study variation in chronic diseases other than cancer, yet it is invaluable for identifying what works across the Nation as a whole as well as locally.
 - Lack of resources prevents the Leadership Initiatives from being able to develop specific programs at a local level that reach out to families dealing with childhood cancers. Coalition volunteers refer families to local health authorities or regional offices; however, this approach is not very effective. Limited resources have limited the focus to cancers with the highest incidence.

Additional Research Needs and Other Recommendations

- The Leadership Initiatives would benefit from having some centralized activities (e.g., training programs) and a network of mentors around the country that could help investigators at the local levels implement programs and address local problems as they emerge. An example of this is a Native American pilot project to develop a survivors' database and related support system. Sites in Santo Domingo Pueblo, the northern Plains, Alaska, Arizona, California, and Wisconsin are participating and will share data. Initial findings suggest that many subgroups are not able to access state-of-the-art treatment (e.g., very few women with breast cancer are on tamoxifen). A central coordinating organization would be of significant benefit. Having an actual "leadership" initiative, rather than only a "network" with funds limited to one meeting of 13 members per year, has delayed collaborative initiatives such as the survivor's database.

CONSUMER CONCERNS FOR THE FUTURE: THE VOICE OF ADVOCACY

National Coalition for Cancer Survivorship

Background

Founded by and for survivors, the NCCS mission is to advocate on behalf of people with all kinds of cancer. The term "cancer survivorship" is used to represent the state of living with the challenges of the cancer experience. This population is not bound by biological, genetic, or geographic factors, but by many other problems, such as increased risk of

developing second and third cancers. This population is at risk for long-term and late effects of cancer treatment. NCCS' works to generate a nationwide awareness of cancer survivorship (e.g., through publications, education to eliminate the stigma of cancer, advocacy for insurance and employment rights, and empowerment of individual survivors in the communities where they live and work). Illustrative of NCCS success is the increasing responsibility survivors are taking to ensure that their views are heard.

Key Points

- Only in the past decade has advocacy been recognized as a legitimate strategy for influencing the policies that shape health care, and it has only been in the recent past that health care professionals have become aware of the need to stand with the patient advocacy groups to ensure the provision of quality cancer care.
- In the classic sense, advocacy means summoning to one's assistance, calling to one's aid, or defending. In health care, advocacy is the act of informing and supporting persons so that they can make the best decisions possible for themselves. In cancer survivorship, advocacy is a continuum that spans personal, organizational, community, and public advocacy.
- Personal advocacy entails empowerment. For cancer survivors, empowerment can mean the difference between maintaining a positive future outlook or feeling helpless and less sure of the desirability of survival. Cancer-related self-advocacy is essential in the current health care delivery system. Despite some legislative successes (e.g., the Family and Medical Leave Act, the Health Insurance Accountability and Portability Act), much needs to be done to teach patients how to obtain quality cancer care in a managed care environment.
- Patients and their caregivers need to be educated about advances in cancer care, such as participation in clinical trials. Not all HMOs will cover costs associated with clinical trial participation, and many physicians are uninformed about trials. Some patients erroneously believe that the control group in a trial receives no treatment, but is given only a placebo with no active ingredient.
- Clinical trial insurance coverage issues are confusing to payers, physicians, and patients alike. Patients and physicians report that they avoid telling the health plan that care is being provided under the auspices of a trial in order to obtain reimbursement for services. Some physicians may be reluctant to refer patients to trials because they fear losing a patient, are unaware of trials that may be relevant to the patient's disease, or are skeptical about the care provided in trials.
- At the organizational level, advocacy for coordination of services and for the provision of support services is important. Institutions are cutting back on providing the services of oncology social workers, oncology nurses, and pastoral care counselors. As hospital lengths of stay decrease, there is less opportunity for preventive interventions that previously were used to help patients adapt to living with cancer. Cancer survivors can help in advocacy efforts by speaking at medical schools, in the media, and at professional meetings about the needs and issues of cancer survivorship, and by educating employers, unions, and community groups about the need for better managed care plans.

- Followup cancer care is another important area for community advocacy; followup clinics for long-term survivors are urgently needed. The NCCS publication, *Imperatives for Quality Cancer Care: Access, Advocacy, Action, and Accountability*, identified needs for quality cancer care, physiologic long-term effects of cancer treatment, and psychosocial issues of cancer survivorship. One of the most significant needs identified was for clinics that focus on health promotion, disease prevention, rehabilitation, and physiological and psychological problems.

Additional Research Needs and Other Recommendations

- As advocates for their own care and the quality of their lives, cancer survivors must have a collective voice in helping to shape health care policy and standards of quality cancer care.
- At the community advocacy level, there is an urgent need for the development of new models of cancer control for the medically underserved. These programs must be culturally and educationally appropriate. Many excellent examples are available; however, many more are needed.
- Access and coverage for clinical trials participation often becomes a political advocacy issue. Despite their potential for improved survival or an enhanced quality of life, many insurance plans arbitrarily refuse to cover routine patient care costs associated with clinical trials, leaving many individuals without the means to afford the best treatment available. NCI must join with advocacy groups to develop a joint plan of action to maximize leverage with both public and third-party payers for clinical trials.
- Increased funding for behavioral research, particularly survivorship research, is needed.
- Cancer survivors have a great deal to contribute - to advocacy, and to further oncology research, education, and practice. They need to be included in the design of research studies and clinical trials. They have much to contribute to institutional review boards, hospital ethics committees, and commissions and advisory groups. They should be included in negotiations with managed care companies and with those writing legislation about cancer care. They belong as partners in teaching institutions and community organizing efforts. The establishment of the Director's Liaison Group within NCI is an excellent example of the partnership that needs to exist between the professional oncology community and the consumer.

US To International, Inc.

Background

In existence for 6 years, US TOO is the largest men's cancer organization, with more than 100,000 members and over 550 chapters. The recent increases in prostate cancer incidence rates are due in part to the aging of the population, but are related primarily to the increased diagnosis of asymptomatic men as a result of the prostate specific antigen

(PSA) test. Between 1988 and 1991, physicians increased their use of this test for men over age 65 from 1,430 tests per 100,000 men to 18,000 tests per 100,000. Prostate cancer incidence now appears to have peaked, as many men now receiving the PSA test have already received at least one prior test.

For organizations like US TOO, and for many individuals facing even the possibility of prostate cancer, early detection has become a mantra. The majority of American men are already aware of the importance of testing. The challenge now is to inform them of their options after they have been tested and/or diagnosed. Different treatments impact greatly on men's quality of life. The decision to seek treatment, and what kind of treatment, is as much personal as medical.

Key Points

- Reports of a decline in prostate cancer mortality may be premature, and the attribution of any such decline to early detection may also be premature. NCI researchers indicate that any drop in mortality rates is occurring too soon to be related to increased screening; it will be a few years before the impact of screening on prostate cancer mortality can be assessed. The 5-year prostate cancer survival increases may be easier to explain. A man diagnosed as having Stage B prostate cancer in 1985 would, by 1995, have been considered a Stage C or D prostate cancer patient. This shift reflects improvements in diagnostic techniques and technology. This individual's chances of survival would not be estimated to be nearly as good as a Stage B in 1995. Controversy over early detection continues, but may be moot, since it is now estimated that more than 50 percent of men over age 50 have had at least one PSA test, and that more than 20 million men will have the test this year.
- Adequate information on the natural progression of prostate cancer is lacking (i.e., whether a tumor will be indolent, aggressive, or potentially lethal). According to some, three out of four men diagnosed with prostate cancer do not really need to be treated. Either their cancers will not be aggressive or the treatment will not be effective, or they will die of something else first. The fourth man, theoretically, can benefit from treatment. Unfortunately, we cannot yet distinguish reliably who should or should not be treated.
- Physicians bring different perspectives to the decision regarding treatment, based on their training, experience, and other factors. Oriented to ensuring survival, the physician may place less importance than the patient on the potential for treatment-related impotence, incontinence, or other complications. The patient, however, must ask, "What is my life going to be like if I take this particular route?"
- On diagnosis, men are frequently presented with a relatively simple picture and are encouraged to act more rapidly than is necessary. Men need time to overcome the fear that accompanies a cancer diagnosis so they can make informed decisions based on medical factors as well as personal preferences.
- US TOO has joined with NCI to establish the National Prostate Cancer Education Program, an initiative aimed at men with or at high risk for prostate cancer. A

- newly diagnosed patient should become a member of a support group, which can be instrumental in showing him the importance of actively participating in decision making, understanding the medical factors involved, and accessing information.
- While survey data show that a majority of men prefer a passive role in treatment decision making, they still want to be informed and have their opinions considered by their doctors. It is important to realize that patients and their families differ in their preferences. Some want their doctors to tell them what to do, some want to collaborate, and some want to make the decision. What is less clear is the extent to which the physician's handling of the interaction influences the decision that is made; this area requires investigation. Questions that need to be asked include: Is denial the typical response to a cancer diagnosis? Do patients really want physicians to hide uncertainty or bad news from them? How can patients get the information they need to participate fully in the treatment decision? What impact does better communication between patient and doctor have on health status? Do patients who participate in treatment decisions have fewer problems with impotence or incontinence? Is it possible to link medical outcomes to decisions made as a result of specific communication approaches?
 - Since the treatment decision may impact a man's daily life for 30 years or longer, assuring that the patient's preferences are considered is absolutely essential. Conducted in tandem with medical research efforts to improve diagnosis and treatment, psychosocial research could result in identifying ways that patients and physicians can collaborate, to the benefit of millions of cancer survivors, their families, and their doctors.

Additional Research Needs and Other Recommendations

- Applied research that would benefit men and their physicians struggling with complex treatment decisions includes a better understanding of the natural progression of prostate cancer. This knowledge would enable patients and their physicians to better predict prognosis.
- Better data on the risks or likelihood of treatment-related impotence and incontinence and on alternative methods of addressing these problems are needed. Studies on decision making in the medical literature typically focus on issues faced by physicians. Most psychosocial research in the health field addresses patients= coping skills, compliance with doctors' orders, or behavior modification in response to promotional or educational initiatives. Research on the dynamics of clinical consultation regarding diagnosis, treatment, and prognosis would be most timely.

Discussion

Key Points

- The position of US TOO regarding PSA screening is that men should be informed about the pros and cons of screening and should make their own choices as to whether to be screened. The organization, working with NCI, is trying to develop educational initiatives and other ways of intervening outside the medical setting so that men not in the health care system or without physicians (e.g., the poor or otherwise disadvantaged and special populations) can learn about the issues surrounding screening and make informed choices.
- US TOO maintains a site on the World Wide Web at www.ustoo.com.

National Asian Women's Health Organization

Background

The National Asian Women's Health Organization (NAWHO) is a nonprofit organization committed to improving the health of Asian-American women and girls. NAWHO focuses on bringing people together to create strategies that will close existing gaps in health care for this underserved population. The specific health care needs of Asian-Americans have often been overlooked because of stereotypes; among the most misleading being the "model minority" myth that all Asian-Americans are wealthy, educated, and healthy. This is simply not true for vast numbers of Asian-Americans in this country and masks the enduring barriers and problems that Asian-Americans encounter.

In the fall of 1996, NAWHO brought together 45 leaders at the first National Asian-American Breast Cancer Summit. This meeting was a joint effort between Government agencies, such as NCI and CDC, the private sector, health care providers, community-based organizations, and advocacy entities. From this meeting, a National Plan of Action on Asian American Women and Breast Cancer was created that systematically addresses all aspects of access to and involvement with breast cancer education, detection, and treatment services. This plan has been created to assist other agencies serving Asian Americans in national efforts to advance research on breast cancer and to encourage women's proactive consumer involvement in these processes.

Key Points

- Some people wrongly assume that Asian-American women do not get breast cancer. Data presented earlier showed that heart disease was the leading cause of death for all female populations; however, Asian-American women are the only group for whom cancer rather than heart disease is the leading cause of death. Rates vary widely among population subgroups: Hawaiians have a breast cancer

- incidence rate of 105 per 100,000; in Japanese women the rate is 82 per 100,000; for Korean women, the rate drops to 28.5 per 100,000.
- Changing demographics call for a new perspective. It is not possible to adjust statistics for breast cancer on the basis of immigration status. While breast cancer incidence and mortality rates for immigrant Asian women are the lowest of all women in the United States, the longer Asian women are in this country, the more likely they are to develop breast cancer.
 - Vietnamese women have the highest rate of cervical cancer in the United States. There are no data, however, on cervical cancer mortality rates for either Vietnamese women or Korean women, who have the second highest incidence rate for this disease (15.2 per 100,000). We do not even know the number of women from Asian/Pacific Islander populations who are dying from cervical cancer or if they are receiving appropriate treatment.
 - Asian-American women have the lowest rates of Pap test screening, mammography, and clinical breast examination of all racial and ethnic groups in the United States. Asian women are greatly underrepresented in breast and cervical cancer research and in screening and outreach programs. Low screening rates result in too many women being diagnosed at later stages of disease.
 - Most Asian women do not perceive themselves as being at risk for health problems and are not getting sufficient baseline information from their providers about screening and preventive health care. Maintaining personal good health is not a cultural priority. Health professionals need to become advocates in changing gender-based and culturally based attitudes toward preventive care, including breast and cervical cancer screening.
 - NAWHO conducted a knowledge, attitude, and belief survey regarding reproductive health care services involving 734 Asian women between the ages of 18 and 35 in six California counties. More than 25 percent of these women had never had a gynecologic exam. Over 49 percent had not had a physical or gynecological exam in the past year. Of those who were sexually active, 69 percent were not always protecting themselves against sexually transmitted diseases (STDs). When asked why, they said they felt they were not at risk for STDs. Of these women, 50 percent had private insurance; however, even among this educated and insured population, utilization of preventive health care was very low. Outreach and screening efforts must incorporate cultural competency to increase Asian women's perceptions of the value of interacting with the health care system, and to overcome the lack of information, fear, misconceptions, and cultural barriers that currently result in underutilization of available services.
 - The HP 2000 targets aim for an 80 percent rate of clinical breast exam and mammography among Hispanic and black women; however, Asian women have not been included, nor have they been included in Pap test special population targets.
 - National studies show that Asian-Americans have the lowest rate of smoking (13.9 percent) of all racial groups. However, subpopulation studies have shown much higher prevalence rates C over 50 percent C for certain ethnic-specific populations, including Laotians and Cambodians. Since many studies use

- telephone surveys in English, with mostly middle-class respondents, it is quite possible that many immigrant and refugee communities have been overlooked.
- Since most Asian-Americans are immigrants, smoking behaviors in their countries of origin must be studied. While smoking rates have fallen in the United States, Great Britain, and Australia, in Asian countries tobacco use has increased by 22 percent. Cigarette advertising is pervasive in Asian countries, encouraging practices such as handing out boxes of cigarettes at weddings, and using tobacco as a healing tool in Laotian communities. Studies in California show that tobacco billboard advertising is most prevalent in Asian-American neighborhoods compared with other racial groups.
 - Tobacco control is a crucial issue for Asian-American women that has received inadequate attention. Lung cancer is the second leading cause of death for Asian-American women, and ranges between second and third among different Asian ethnicities as the most commonly diagnosed cancer. This has particular implications as the relatively young Asian-American female population ages. The majority of these women are of reproductive age. As children of immigrants, in the home girls grow up in smoking environments that are carried over from Asian countries. Outside the home, they face the media image of thin, beautiful women - beautiful women smokers - as social ideals, combined with pressure to acculturate and fit in with their American peers.
 - NAWHO has organized a series of cultural competency training sessions for health care professionals in California. The core message is to recognize language as a primary barrier to effective breast and cervical cancer screening outreach to the State's Asian population. Language barriers, however, are not the only concern. While Asian-American community-based clinics can provide comprehensive, culturally sensitive, and bilingual care, it is not realistic to expect that all Asian women will be served by these providers, nor to expect that every provider has the resources to provide translation for every Asian language. Rather, compassionate and respectful efforts to provide information and services is critical to increase utilization and bring about changes in behavior.

Additional Research Needs and Other Recommendations

- Expand investigations into the increase of breast cancer in Asian women, with an emphasis on risk factors and intergenerational risk. Studies to gain a better understanding of the lower risk for women residing in Asian countries and the increase in the risk over time after migration to the United States hold immense potential for understanding how breast cancer might be controlled. This research would benefit all women.
- Strengthen the capacity of the NCP and SEER for the collection and use of ethnic-based data on breast and cervical cancer incidence and mortality among Asian-American women.
- To address tobacco use among Asian-American women, NCHS and the national vital statistics system should expand their efforts to collect ethnic-specific and gender-specific data among Asian immigrant and refugee groups. Further,

- Government agencies should target tobacco control education resources towards younger Asian-American women and girls who are at risk for tobacco use.
- HP 2000 goals should be updated to include Asian-American women in all priority areas.

North American Brain Tumor Coalition

Background

The North American Brain Tumor Coalition (NABTC) comprises eight brain tumor research and patient service organizations. The statistics on children and adults with brain tumors are disheartening. The incidence of brain tumors seems to be increasing, a fact not explained by the aging of the population. The death rate is increasing rather than decreasing.

The statistics on brain tumors mask the complexity of the disease and the challenges associated with its treatment and aftermath. Brain tumors include many subtypes of disease. Different tumor types grow at different rates and respond differently to treatment. This year, 17,600 Americans will be diagnosed with primary malignant brain tumors, the most aggressive type. Only 25 percent of those with this diagnosis survive for 5 years. For the more than 10,000 adults who are diagnosed with primary benign brain tumors each year, many will not survive because the location of the tumor precludes surgery. Benign tumors may recur and may become malignant. Another 80,000 individuals are diagnosed each year with metastatic brain tumors. Individuals with either primary or metastatic brain tumors face similar treatment hurdles and side effects.

For children, the picture is even more complex. Brain tumors in children are very different from those in adults in their origin, growth, and response to treatment. Brain tumors are the most common solid cancer in children, and, depending on the type, pediatric brain tumors are among the most aggressive. Brain tumors are the second leading cause of death in children up to the age of 15 years as well as for young adults between the ages of 15 and 34 years.

Key Points

- The location of the tumor directly and indirectly affects every system of the body, complicating and limiting treatment. Treatment involves consideration of the impact of the treatment itself on the surrounding tissue and on the functions the tissue subsumes. Surgery, while often the most effective treatment, may not be an option for many, because the location of the tumor may affect functions critical to the quality of life or to life itself. Improvements in surgery, radiation, and chemotherapy have reduced deaths and boosted survival for other cancers, but these trends have not been achieved for brain tumors.
- Treatment presents another serious challenge in that the relatively small numbers of brain tumors (as compared to other types of cancers) are not an attractive target for private-sector investment and new product research and development. This

- year, the FDA approved a new delivery system for chemotherapy, the first new treatment for brain tumors in 7 years.
- Although the survival rate for children is higher than for adults (60 percent versus 25 percent), survival rates for children with brain tumors have not improved as dramatically as they have for many other childhood cancers. Treatments for children raise difficult ethical as well as medical issues. These include the potential toxic and damaging effects of therapies on a child's developing brain. Families must evaluate the impact of treatment on their children's quality of life and future. While children with certain types of tumors may respond well to treatment with relatively few side effects, children with other types may be seriously disabled by the disease and its treatment.
 - The individual organizations comprising the NABTC have awarded more than \$18 million in brain tumor research funds for solid, creative research on basic science questions related to brain tumors.

Additional Research Needs and Other Recommendations

- A two-pronged approach to brain tumor research is needed - there must be a greater sense of urgency regarding the development of new treatments, and there must be focused basic research to uncover the causes of brain tumors. NCI has acknowledged the need for this dual approach in planning its research agenda.
- Discovering the genes and growth factors associated with many different types and sites of cancer holds potential for developing therapies that may apply across cancers. Research also must be conducted to deepen our understanding of specific cancer types so that new therapies can be tailored appropriately using new knowledge as it becomes available.
- For brain tumor patients and their families, time is often measured in days and weeks, rather than in months and years. As a result, this special population is impatient with the bureaucratic response to date to pleas for better treatment. While it is appreciated that scientific discovery cannot be rushed, NABTC urges policymakers to take a fresh look at old and seemingly insoluble problems in an effort to create the best possible environment for basic and clinical research and accelerate the translation of basic science discoveries into improved therapies. Coordination between basic researchers and clinicians is essential.
- The Federal Government should target basic research on brain tumors in both children and adults.
- Incentives for industry and for private-public collaboration should be enhanced to develop better therapies; there should be incentives in the form of additional exclusivity to expand labeling of drugs for pediatric use. Ready access to information about off-label drug use may be of particular importance for children.
- Both private-sector and Medicare insurance programs should be encouraged to allow enrollees to participate in clinical trials, with coverage for routine patient care costs.
- Continued strong support for the pediatric clinical trials network for brain and other solid tumors is needed.

- A new and efficient national clinical research strategy should be created to develop and assess new treatments for children with brain and other solid tumors.

Intercultural Cancer Council

Background

The Intercultural Cancer Council (ICC) is a unique organization that brings together leaders and experts from minority and medically underserved communities, along with experts from mainstream cancer medical, scientific, and survivor organizations to focus on the cancer problem in minority and medically underserved communities. It is clear that individuals from racial/ethnic minorities, the poor, and/or the medically underserved have not shared equally in the progress that is being made against cancer. ICC works to reduce the high incidence of cancer and its associated suffering and death by promoting policies and programs that address this imbalance. While poverty does have a great impact on cancer, it is by no means the only significant issue. In looking at the problems we face, we need to think "outside the box."

Key Points

- For consumer advocates for minority and medically underserved populations (with a personal stake in the issues), the belief that cancer research will yield results that are relevant to these populations, their families, and their communities, is of utmost importance. While it is understood that a great deal of information is not yet known, the cancer problem is urgent, and is growing more so in America's increasingly diverse and disenfranchised racial and ethnic populations.
- An effective interface between science and public health systems is critical. The heart of the issue is the speed at which research results are applied to cancer prevention and control programs in communities. How this is approached, along with the priority assigned at the national level, determines how many lives can, in fact, be saved.
- There is a lack of central, baseline data on the cause of the disproportional cancer rates among minorities. These differences cannot be attributed solely to "inadequate access."
- ICC supports enhancement of the State Cancer Registries so they can collect necessary data addressing relationships between environment and cancer. The ICC also is encouraged by NCI's current efforts to create a task force to review surveillance data collected by SEER.
- Data on dietary habits and minority populations are constantly changing, as subgroups move around the country. Surveys conducted at one point in time may not be representative or accurate for specific geographic areas or for particular groups. This presents a continuing challenge for those conducting research on the effects of diet on cancer.

- Being aware of the subtleties inherent in data on cancer rates is essential. Geographic differences, dietary habits, immigration status, and many other factors must be taken into account. For example, Hispanic Americans in Illinois have the highest breast cancer incidence in the nation, yet nationally, Hispanic women have among the lowest breast cancer rates. Similarly, in Texas, more than 30 percent of breast cancer deaths among Hispanics and blacks were in women under age 50, twice the percentage for white women in the State.
- Although the notion that health risk often varies by race/ethnicity was considered potentially inflammatory a decade ago, it is now widely accepted. We should not be ashamed to notice differences in health risk; the shame is in not noticing them. From the ICC's perspective, the issues in addressing cancer risk in minority populations are not issues of social change, but of investing in America and its people.

Additional Research Needs and Other Recommendations

- The NCP is more critical than ever in terms of program planning, integration, implementation, and accountability across all Federal agencies and the private sector. Who is in charge of the program? Finding a locus for the NCP, where turf issues, funding, and program priorities can be agreed upon, is critical. The ICC would like to be a part of discussions aimed at revitalizing the NCP in this way.
- The Asian American/Pacific Islander group is the only racial/ethnic minority population that is not served by a Leadership Initiative on Cancer. The Panel should take action to rectify this inequity.
- Recent funding decisions to increase resources for the ALIC and decrease them for the NHLIC are not acceptable. Funding for all of the Initiatives should be increased, not increased for one at the expense of another. This issue must be addressed.

Discussion

Key Points

- One example of providing incentives for private industry to pursue brain tumor research can be found in the recent FDA reform legislation that provides 6 months of market exclusivity for developers of drugs for the treatment of pediatric brain tumors. The success of this incentive in spurring drug development efforts for this small patient population remains to be seen, but it is a step toward improving the environment for brain tumor research.

CONSUMER CONCERNS FOR THE FUTURE: ISSUES FOR RESEARCH AND MEDICINE

American Medical Association

Background

As part of its mission to improve public health, the American Medical Association (AMA) supports educational initiatives to educate minority populations with regard to their cancer risk. In its advocacy role, the AMA consistently supports funding for the NIH. The AMA also recognizes and is highly invested in addressing the need for coordination of clinical research and clinical trials. To this end, the AMA, along with the American Association of Medical Colleges (AAMC) and Wake Forest University, is convening a summit on the future of clinical research. The AMA also supports the goals of HP 2000, and is highly involved in tobacco use issues, supporting Smokeless State Programs and funding for smoking cessation programs.

Key Points

- The educational poverty of physicians with regard to cancer genetics, particularly given the accelerating trend toward marketing cancer-related marker tests directly to physicians and patients, is a major concern. To illustrate, a study reported in a 1997 article in the *New England Journal of Medicine* indicated that a significant proportion of the providers studied would have misinterpreted a test for APC, a colorectal cancer gene. Currently, there are only about 2,000 genetic counselors, most of whom have been trained principally in prenatal genetics, and only about 1,100 medical geneticists. The AMA believes this situation represents a major crisis in cancer genetics education in this country.
- In response, the AMA has joined with the National Institute for Human Genome Research, the American College of Medical Genetics, the American Society of Human Genetics, and primary care provider organizations to sponsor a March 1998 conference on genetics and genetic testing. One-half day of the 2 day program will be devoted to cancer genetics. A strong impetus for the conference was the recognition that the medical school education of some physicians may not have included genetics. In addition, physicians need to know what questions to ask patients who have family histories or potential predispositions to cancer. Physicians need to know how to interpret data in the literature on the penetrance of specific cancer genes, the cancer risk associated with them for specific populations, and the performance of new gene tests. Misinterpretations of risk (e.g., Ashkenazi Jewish women with BRCA gene mutations) may lead to inappropriate treatment. In addition, patients are now, through access to the Internet, becoming informed about cancer genetics issues; physicians must be able to knowledgeably discuss these matters with their patients. In a related activity, the AMA, the National Coalition on Education of Health Care Providers, and the American Nurses Association have joined forces to provide reliable Internet resources on genetics, including cancer genetics.

- In the drive to collect better demographic and followup data on various populations, privacy and confidentiality concerns must not be forgotten.

American Society of Clinical Oncology

Background

The American Society of Clinical Oncology (ASCO) represents more than 12,000 physicians involved in the day-to-day care of people with cancer, and is dedicated to reducing the impact of cancer on the American public. ASCO is concerned that reductions in cancer mortality rates and other advances are not being shared across all segments of our population. It is critical to understand why these differences exist and correct them.

Key Points

- Socioeconomic differences, while important, do not account for all variations in cancer outcomes. For example, African-American men are at higher risk for prostate cancer mortality and less favorable survival than are white men. A large study of military personnel found that even with equivalent stage of disease at diagnosis, equal access to health care, and treatment by the same group of physicians, the African-American prostate cancer patients had lower disease-free survival. This study suggests that biologic issues might explain some of these differences, both in prostate and other cancers. Any such differences should be sought out and if they exist, they should be well-characterized and therapeutic strategies should be developed to circumvent them.
- Certain prognostic markers for cancer have been identified. One of these is the erb-B2 growth factor for breast cancer, the overexpression of which is associated with poorer outcome, especially if chemotherapy dosage is modest. However, it has been discovered that the adverse outcome of erb-B2 disappears when patients receive high-dose chemotherapy. Many other markers exist; these may be randomly distributed in the population or they may cluster. If they are clustered, different therapeutic approaches may be indicated for certain populations. This is an area ripe for research.
- Advances in molecular genetics have changed our ability to detect individuals at risk for certain cancers from mutations in specific genes. These advances have the potential to lead to new screening and treatment strategies. It is already known that some mutations are not randomly distributed; certain populations (e.g., the Ashkenazim) have unique spectrums of genetic change. Screening of a specific population is made easier if researchers know where gene mutations of interest are clustered.
- Other so-called "founder" mutations have been discovered in subpopulations and could explain some of the observed differences in cancer incidence and, perhaps, outcomes. Access to these populations for research purposes is greatly needed. Considerable suspicion toward genetic testing exists in some communities. These attitudes must be understood, studied, and overcome so that research can go

- forward. The Panel could help in this regard by endorsing the application of molecular biology and molecular genetics as part of the systematic study of possible population differences in cancer appearance and outcome.
- Clinical trials are the accepted vehicle for assessing the efficacy of treatment for any population. If clinical trials are large enough, subpopulations can be studied and compared to other populations in the trial. Many trials, however, are not large enough to generate sufficient statistical power on special populations to support conclusions. In addition, less than 3 percent of adults with cancer participate in trials, limiting our ability to gather subpopulation data and conduct trials in a reasonable length of time. Exclusion of coverage for experimental therapies included in most insurance contracts, including Medicare, further limits participation. Patients are afraid to go into studies and physicians are reluctant to place them on trials.

Additional Research Needs and Other Recommendations

- Bipartisan legislation is being sponsored to require Medicare coverage for cancer clinical trials approved by NCI, the Food and Drug Administration, the Veteran's Administration (VA), and the DoD. The Panel's endorsement of the Rockefeller-Mack legislation could provide a boost to advocacy in support of the bill.
- Comprehensive solutions to socioeconomic problems of access to the health care system are needed. Screening is of little value if there is no payment mechanism to provide followup or treatment when an abnormality is discovered. Many low-income patients have access problems, leading to treatment delays and poor prognostic outcomes. ASCO advocates for adequate and affordable health insurance coverage for all Americans, a crucial step toward persuading patients to participate in screening and obtain appropriate treatment when it is needed. In addition to treatment of identified cancers, cancer care coverage should include screening, prevention, access to oncology specialists, and oral pain medications after hospital release. It is unconscionable to provide adequate pain medication in the hospital setting, only to release patients to suffer needlessly because their insurance will not pay for orally administered pain medications and they are unable to afford the out-of-pocket cost of purchasing them.
- We must remove the barriers erected by health insurers that discourage patients and their physicians from participating in clinical trials, and we must encourage more racial and ethnic minority patients to enter trials. Suspicion about clinical trials and genetic testing must be addressed.
- Tobacco use is the number one preventable cause of cancer deaths; we must redouble our efforts in tobacco control.

Oncology Nursing Society

Background

The membership of the Oncology Nursing Society (ONS) numbers approximately 25,000 registered nurses and approximately 70 associate members who are not registered nurses.

A core value of the ONS is the right of all individuals to the best possible cancer care. Incorporating multiple world views and preferences into every aspect of care will benefit patients and families. Cultural competence enhances a nurse's ability to provide quality cancer care; this is defined as being sensitive and responsive to issues of race, culture, ethnicity, gender, age, socioeconomic status, and spiritual and sexual orientation.

Key Points

- In their work with diverse populations, ONS members have noted that cancer patients from different populations frequently report substantially different symptoms of cancer disease and highly variable responses to treatment, including the willingness and/or ability to comply with treatment and supportive care regimens. This is both perplexing and disturbing.
- Cancer means different things in different population groups. Communication styles and preferences differ and need to be considered in all informed-consent processes. Social support differs within and between different ethnic groups. Symptoms, concepts of death and dying, and survivorship mean very different things to different populations. Issues of trust and credibility have to do with the "insider/outsider" phenomenon, with outsiders often being researchers. Access to trusted providers who are skilled in cancer care services is another real issue. Many variations in home and community care exist. It is important to explore and understand these variations.
- What is meant by "race" is not clearly defined. This confusion creates barriers to effective research and impedes our ability to generalize study results across groups. Heterogeneity within racial and ethnic groups needs to be better understood, since variations and taboos exist that are related to age, gender, and, in the case of Native American populations, to tribe.
- Minority populations have reason to mistrust research, (e.g., the Tuskegee Syphilis Study); and this historic backdrop must be considered when attempting to develop trust.
- Methodologic problems can arise when the language of the dominant group is different from that of the study population. Tools used in research are often created for and by members of dominant groups and do not translate well to members of other population groups.
- It takes time for researchers to become accepted by a community. Folk healing and alternative approaches to health and wellness are often dismissed or ignored by researchers, leading to a perception of arrogance and ignorance on their part. Often, there is no end product or sense of something being given back to the community C a lack of reciprocity. In many cases, the end of a grant means the end of the program, which can lead to a feeling of abandonment by the group being studied.
- Qualitative research methods are generally used to address cultural and ethnic variables; however, these approaches are still not as well accepted as are quantitative methodologies.

Additional Research Needs and Other Recommendations

- The integration of a world view throughout the cancer trajectory should be promoted. Questions of cultural competence must be asked and answered. Cultural assessment skills and tools should be promoted and integrated into clinical practice.
- Racial definitions require clarification, both for use in the grant process and in reporting.
- Approaches that focus on wellness rather than on illness should be fostered. Approaches that incorporate lay health workers whenever possible and draw on insider/outsider research teams should be encouraged.
- Support within the research process is needed that truly considers population needs and is accepting of qualitative research. The grant rating and review processes should be aligned with the cultural, ethnic, and community norms, nuances, and expectations. There is a need to integrate concepts of mutual reciprocity and to incorporate intervention grants, funding for ongoing programs, information sharing, and the involvement of community organizations.
- Study results should be shared with the group under study as well as health care providers, researchers, and policymakers. As Dr. Burhannstipanov has noted on other occasions, many ethnic and cultural nuances are not described in books; we must learn from being in the community.

National Medical Association

Background

The roles of the National Medical Association (NMA) include promoting policy to address the imbalance in cancer mortality among populations; supporting efforts to ensure continuity and portability of health benefits; promoting increased research participation by minority scientists; increasing consumer participation in clinical trials; fostering provider education on the merits of clinical trial participation; targeting health interventions to the needs of minorities; and providing prevention education programs in a variety of health care settings.

NMA has developed several successful educational programs, including a PSA screening program that offers a musical concert as a participation incentive; a smoking cessation program called "Stop Active Smoking and Take Charge," currently under way in 130 NMA chapters; and a breast and cervical cancer screening project that has given physicians the tools and the ability to reach the underprivileged and underserved.

Key Points

- While cancer deaths have declined nationwide, cancer incidence in minorities and the medically underserved continues to increase. Survival rates in these populations are lower than those for the majority population. Cancer rates are highest among African-American men and among Alaskan Native women. Of the

560,000 Americans who will die of cancer this year (1,500 per day), 62,000 will be African-Americans, and 14,300 will be members of other ethnic minority groups.

- There are scant data to prove or disprove that screening and improved health care access will significantly reduce cancer mortality in minority populations. Professional organizations, advocacy groups, associations, and community organizations must provide strategies to address the needs of minorities and the underserved. All health measures must be improved to produce a decrease in minority cancer mortality rates.
- Minorities and culturally diverse individuals should be involved in the development of policies and programs that may impact their communities. Equal representation of minority population groups in research is needed. This includes addressing disparities in data collection and surveillance of high-risk groups, and developing programs to counteract fear, ignorance, and denial with confidence, knowledge, and involvement.
- Barriers that limit minority participation in clinical trials include: lack of awareness of existing protocols by local physicians; the amount of time required for physicians and staff to explain protocols and consent forms; patients' fear of research; the amount of patient time involved, detracting from home and family responsibilities; and the lack of bilingual providers. Protocols must be set up at convenient times (e.g., evenings and weekends). Providing support for travel-related expenses and financial costs associated with certain diagnostic procedures can be very helpful and should be encouraged.
- Tumor incidence differs among populations, which must be kept in mind when recruiting minorities for clinical trials. Specific protocols for cancers seen in minority populations may be lacking. A lack of understanding of minority knowledge, attitudes, and practices can result in poorly planned protocols.
- Future research should be directed at isolating genes responsible for the development of specific cancers. Once identified, we can develop methods of modifying these genes to prevent disease.

American Association for Cancer Research

Key Points

- The Panel's focus on the concerns of special populations intrinsically involves consideration of genetic, racial, gender, religious, and policy concerns. These are controversial issues. Although some believe that race and race differences in cancer are social and political, rather than biological, Dr. Coffey expressed the belief that biologic differences exist and should be studied.
- Research conducted at Johns Hopkins University has examined androgen receptors in relation to prostate cancer. Androgen receptors contain variations in glutamine repeats. The repeat sequences have been observed to be shorter in cancer patients than in people without cancer. Among cancer patients, these sequences were found to be the shortest in African-Americans, of moderate length in Caucasians, and longer in people from Asia. Further, several distribution

- curves have been identified within different races, suggesting that there may be subpopulations within racial groups. Research at Johns Hopkins and by other investigators suggests that the shortest glutamine repeat links are associated with the race that experiences the most aggressive forms of cancer.
- From an anthropological perspective, it is difficult to classify people by race. All human groups are polymorphic. There is no one human genome, just as there is no one common human. Variations in the noncoding regions of the gene affect gene stability. Thus, polymorphism has a tremendous effect. Genetic differences between various groups exist (e.g., lactose intolerance in some Asians, sickle cell anemia in some African-Americans). Controversy aside, fundamental research should go forward to understand these critical racial differences.
 - Young cancer scientists are fearful of being unable to find jobs. This is not surprising, since currently only 23 percent of approved grants are funded. In the early 1970s, when the war on cancer began, 40 percent of approved grants were funded. Yet, despite the delay in progress against cancer and the disincentives to pursue cancer research careers that are being caused by inadequate funding, there is little support, even in the scientific community, for vastly increasing cancer research funding. Those who suggest that funding should be doubled or tripled are considered naive.
 - Dr. Coffey noted that in the time required to conduct the afternoon's meeting, eight people in the United States would be murdered, 11 people would die of AIDS, and 163 people would die of cancer. The toll of death from cancer is equivalent to five fully loaded Boeing 747 aircrafts crashing every day. Despite the public's perception, there has never been a real war on cancer; what has been done to date represents only a skirmish.
 - Government representatives, specifically the Congress, appear to be uninterested in minority and cancer issues. Likewise, Government policy on tobacco is counterproductive and does not address the need for research in this area.
 - Investments in cancer research have paid off (e.g., finding a cure for testicular cancer). Can funding be found to solve the riddle of the six leading cancers? Finding effective prevention and cures requires a major policy shift, including greatly increased funding for research - a real war on cancer.

Discussion

Key Points

- The NMA believes that increasing physician awareness and understanding is one way to increase the number of adults in cancer clinical trials, and has partnered with the Eastern Clinical Oncology Group (ECOG) in this regard. ASCO is focusing on the passage of legislation to cover clinical trial care costs. It also supports the cooperative group research programs, such as ECOG, that can also make a key difference in easing barriers to trial participation for both physicians and patients. The AMA believes that patient empowerment can be effective in increasing understanding and confidence in the clinical trials mechanism. Support

organizations that track the availability of clinical trial programs are providing an important source of information for patients.

- ONS members are aware of and actively support patient access to clinical trials. ONS is collaborating with NCI on a workshop to help nurses provide patients with consistent information about clinical trials generally, and with regard to specific protocols. In addition, the ONS Clinical Trials Special Interest Group is working with NCI to assess the informed- consent process for clinical trials. ONS also supports reimbursement for direct care costs of clinical trials participation.
- Dr. Coffey expressed his view that should funding for cancer research be dramatically increased, the funds should be put into existing programs (e.g., in biology, epidemiology, molecular research). The number of Specialized Programs of Research Excellence (SPOREs) should be increased for cancers such as prostate. At the same time, there is a need for fresh thinking to accelerate progress.
- It has been known for 20 years that prostate and breast cancer rates increase in populations that move from Japan to Hawaii, and jump again when these same populations then move to the U.S. mainland. The scientific reasons for the associations are not known, but with adequate resources applied at the levels of basic research, prevention, and therapeutics, questions such as these should be answerable.
- The patient accrual rate by physicians participating in clinical trials is about 9 to 10 percent of all patients seen. Minority participation in NCI-sponsored trials is proportionally representative to the burden of cancer in these populations relative to the population as a whole. Dr. Brawley expressed his view that the tendency of blacks and other minorities to be suspicious of medical research is more likely to be related to their personal encounters with the medical system than fears engendered by the Tuskegee Syphilis Study. Remedies being pursued by the NMA include conducting regional outreach, emphasizing prevention, teaching healthy lifestyles to school-aged children, and promoting clinical trials.
- The advent of managed care has increased problems with patient accrual to clinical trials. Rhode Island has passed legislation that requires managed care entities to support routine care costs of any patient on approved Phase II, III, and IV clinical trials. Approximately 12 other States are exploring the passage of similar laws.
- If alternative and less toxic therapies were given the same value and respect as surgery, chemotherapy, and radiation, there might be greater public interest in research participation. The need for less toxic therapies is well recognized; researchers are looking for naturally occurring factors, such as cytokines, and other biologicals that will affect cancer cells without harming normal cells.
- Categories used in the United States to define race are not biologically determined; rather, they have come out of the Nation's history. Eighty-five percent of genetic variation occurs within a given race; 15 percent occurs between races. Groups of people are different; but race is not the classifier that determines the difference. However, stating the issue in this way can suggest that there are no genetic differences between African-Americans and Caucasians when clearly there are. Differences in polymorphism are seen in different racial groups. There

- is at once a tendency to de-emphasize race distinctions and to believe that racial and cultural differences are unique and important in understanding cancer causation. These two perspectives are not necessarily diametrically opposed.
- For the cost of one B2 Stealth bomber, we could double the budget of the NCI.

Closing Remarks

In his closing remarks, Dr. Freeman highlighted aspects of the day's presentations and indicated that:

- The Nation's cancer problem is large and involves all populations - this year, there will be more than a million new cancer cases and more than a half million deaths. While there has been a 2.6 percent reduction in cancer mortality over the past 5 years, this reduction has not been evenly distributed across all parts of the population. We need to determine the reasons for these discrepancies and, at the same time, attempt to improve conditions for all populations.
- The testimony provided at this meeting, and the Panel's recommendations based upon it, will be incorporated into a report to the President.

I certify that this summary of the President*s Cancer Panel meeting, Concerns of Special Populations in the National Cancer Program: The Real Impact of the Reduction in Cancer Mortality, held on September 29, 1997, is accurate and complete.

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