Statements from the President's Cancer Panel

Meeting

The Responsiveness of the Health Care System to the Needs of Special Populations

On November 21, 1997, a plea for "health, not Stealth" was made to the President's Cancer Panel on behalf of all Americans fighting cancer. Those making the plea compared the annual budget of the National Cancer Institute, approximately $2.3 billion, with the $2 billion cost of a single Stealth fighter plane. "We must continue to support cancer research" suggested Dr. Harold Freeman, Chair of the PCP, "in order to give future populations the hope of conquering cancer, even if they currently fall into a group for whom there are currently few answers." The point was made, resoundingly, that the war against cancer is very real battle--cancer claims nearly 600,000 lives each year, and incidence rates are in excess of 1.2 million, annually.

The need for a general increase in cancer research funding was one of several recommendations made to the PCP at this last in a series of four meetings addressing concerns of special populations in the National Cancer Program (NCP). Other recommendations included: reexamining the definition(s) of "special populations" and the manner in which research is conducted and reported in relation to the underserved of this Nation; legislating access to clinical trials in all managed care programs; defusing competition among cancer advocacy groups in favor of a balanced research agenda; designating academic health centers as "endangered" and identifying strategies to help them survive; providing more support for public health services, since no one is "competing to serve the uninsured"; and pursuing strategies to attract researchers and specialists back into the NCP.

The question was raised of how to define "special" populations for which there are unusual or "special" research concerns. Such populations have traditionally included minorities, the elderly, the poor, the uninsured, and the underserved. But the challenge of defining "special" populations has become increasingly complex as this Nation becomes a more multiracial society and as scientists try to account for socioeconomic and cultural factors in scientific evaluations. Some presenters challenged the usefulness of the current designations in addressing important research issues. There are clearly local variations in the groups that do not fit traditional definitions, but that still merit special attention. In Western Florida, for example, the concerns and the health issues of migrant farm workers and children are considered "special," yet health care research among these groups is not a routine part of cancer research. The broad designations scientists have traditionally employed also fail to discern subgroups that have special needs within larger general groupings. In Montana, for example, "reservation" Native Americans present different concerns and have different needs from Native Americans as a whole.

A related issue raised is how to define "minority" special populations-a subject addressed at an earlier PCP meeting this year. Current definitions are socially and politically constructed, and were not intended to answer scientific questions. Debate continued over whether the grouping of individuals by race/minority status based on self-reporting in an increasingly multiracial society has scientific merit. On one side it was argued that such classifications are unreliable and ignore socioeconomic, educational, cultural, and other important factors. On the other side, we heard that while it may be difficult to accurately classify people into different racial and ethnic categories, it is important to look at race as a surrogate for differences in cancer outcome.

One recommendation made was to target funding toward well defined groups to help answer specific research questions, rather than drawing population-specific scientific conclusions from larger studies that "add on" a small minority or special population components. Other speakers urged the Panel to continue supporting research targeted at special populations, despite the questions being raised, "because this designation allows access for many underserved populations to NCI protocols."

The debate over managed care continued as part of the day's deliberations. Most speakers testified that the current health system is not responsive, nor friendly, to the needs of the majority of the population. Chronic problems cited included delays in referrals, denial of costs associated with clinical trials, incomplete workups, use of remote or contract testing sites, and "hassle" factors in navigating pre-authorization and reimbursement systems. Advocates testified that patients and providers are weary of fighting for access, rather than being able to fight their disease. They suggested that "responsible care" be defined and required of managed care organizations in order to bring integrity back into the health care system. It was strongly recommended that managed care organizations also contribute to the costs of clinical research, if they intend to reap its benefits. This should be done on a national level through legislation.

The Panel heard testimony about the impact of managed care systems on academic health centers (AHCs) and public health institutions. Diversion of patients (including Medicaid/Medicare beneficiaries) from these institutions to HMOs leaves little income flexibility to shift the costs of care for the indigent and uninsured, and, for AHCs in particular, to maintain clinical cancer research.

AHCs are also experiencing a decline in medical students seeking specialty and clinical research careers. The current managed care health system does not encourage or reward such career paths. This is critical, since the training of researchers and specialists cannot be halted and then "turned back on." An appeal was made for a national review of the academic health research enterprise and how it can best serve the needs of this Nation.

Broad concerns over the future of cancer clinical research were raised-concerns that have been shared before. Shifts are occurring among private physicians and academic health centers to commercially sponsored clinical trials that provide high per-patient payments and low levels of paperwork. While such studies answer well-defined scientific questions, they are designed from a commercial perspective, and important cancer research questions may be left unanswered.

A call was also made to depoliticize advocacy issues--to try to maintain a balanced agenda in promoting specific needs while furthering the overall cancer research agenda. Given existing funds, the question was raised of how special interest and advocacy groups can be joined together under a common umbrella to fight for the overall needs of all who are challenged by cancer.

Overall, testimony indicated that no specific effort is being made to respond to traditionally defined special populations under the current health care system. Rather, those that have been most disenfranchised, the poor and uninsured, are becoming further removed from the health care system as resources are shifted from the institutions that serve these populations to managed care centers. For-profit managed care organizations continue to decline voluntary investment in clinical cancer research efforts, and cancer patients experience significant difficulties gaining access to appropriate treatment and care. As one presenter eloquently stated, "all Americans are a special population in the current health care system if they become ill with cancer."