

Statements from the President's Cancer Panel

Improving Cancer Care for All: Real People, Real Problems March 8-9, 2001

"Do we have to give up our dignity to get help with cancer?" A breast cancer survivor's degrading experiences in seeking treatment led her to pose this question to the President's Cancer Panel during regional hearings held on March 8-9, 2001, in Albuquerque, New Mexico. Prejudice and insensitivity based on a patient's income, race, or English proficiency often result in late diagnosis, misdiagnosis, and failure to provide adequate information and referral. One African American speaker's symptoms were attributed to a history of sexually transmitted disease, in spite of the fact that she had no such history. Others reported that they were accused of drug addiction or welfare fraud as a result of their attempts to obtain care. This was the sixth in a series of regional meetings in which the Panel is seeking testimony from patients, survivors, family members, health officials, and health care providers to provide a human dimension to the problem of cancer-related health disparities.

According to many speakers in this region, the population most vulnerable to inadequate cancer care is the working poor. It was noted that increased funding for cancer research "does not always translate into better care for those in impoverished communities." Many of the working poor face hardships because of conflicting eligibility standards for state and federal programs. Patients wait two years to become eligible for Social Security disability income; then they are "too wealthy" to receive Medicaid. When eligibility for state programs is based on outdated federal baselines, patients lose their coverage when the minimum wage rises or SSI payments increase. One speaker lost her state health insurance because her Social Security income was 66 cents over the amount allowed. The Panel learned that both the public and the professionals who serve them are confused about the myriad complexities, and sometimes inconsistencies, in the eligibility criteria and benefits of Medicare, Medicaid, Social Security, and state programs.

The states represented in this regional meeting-Arizona, Arkansas, Colorado, Louisiana, New Mexico, Oklahoma, Texas, and Utah-are home to many Native Americans, and their unique problems were a major focus of the presentations and discussions. Accurate cancer incidence in this population does not exist; available statistics suggest that, while incidence may be lower than in the general U.S. population, the mortality rate is higher. Much of the dialogue centered on the Indian Health Service, described as "the only game in town" for most Native Americans, but also characterized as an agency that lacks adequate funding and staff to serve its constituents. IHS expenditures per client were said to be only 60 percent of the amount spent for people covered under Federal employee health benefits.

IHS funds are part of the discretionary portion of the U.S. budget and levels change

yearly. When limited IHS clinic services cannot address patients' needs, IHS refers patients needing specialized diagnostic and treatment care to contract facilities in non-Native communities (sometimes at a great distance). Many Native Americans testified that they are not treated with dignity or cultural understanding at the contract facilities; even those with insurance often continue to use IHS services rather than seeking outside care. Confusion over eligibility is a continuing problem; while recent legislation provides treatment funding for uninsured women diagnosed with breast or cervical cancer through CDC screening programs, it is unclear that Native American women qualify for this support, because their eligibility for IHS services may be considered insurance coverage.

As the Panel heard in other regional meetings, many IHS doctors are required to work in agency clinics to pay off student loans and leave as soon as that obligation is over, compromising trust and continuity of care. Several speakers argued for solutions to come from Native Americans, with an aggressive and stable Federal program to recruit, fund, and retain Native American physicians. Others said that the IHS needs enabling authority and funds to reduce delays in access to cancer care, become better informed about availability of clinical trials, and work with registries and tribal communities to improve data collection and patient outcomes.

The President's Cancer Panel, an advisory group established by Congress to monitor the Nation's efforts to reduce the burden of cancer, reports directly to the President on delays or blockages in that effort. The Panel is currently holding a series of regional meetings to explore problems that prevent us from getting the best known cancer care to all people. For more information, visit the Panel's web site at <http://deainfo.nci.nih.gov/ADVISORY/pcp/pcp.htm>, call 301-451-9399, or e-mail to pcp-r@mail.nih.gov.