Statements from the President's Cancer Panel

Meeting to Assess Concerns of Special Populations in the National Cancer Program

Coping Strageties for Maintaining Outreach, Information Dissemination, Teaching, Recruitment, and Care in Today's Health Care Environment

As in other regions in which the President's Cancer Panel has heard testimony, increased managed care penetration in the Southeast United States has evoked feelings of both optimism and distress. In its final meeting addressing the impact of managed care on cancer research and patient care, many concerns were reiterated to the Panel, and some new concerns raised. Solutions, however, remained elusive. Presenters focused specifically on how managed care is affecting the ability of the cancer research community to maintain outreach, information dissemination, and education.

Testimony indicated that for-profit managed care organizations are generally not investing in prevention and outreach activities, despite continued profit-shifting in their direction. "These programs are easy to ignore," noted Dr. Otis Brawley, Assistant Director of the Office of Special Populations at the National Cancer Institute, "since they don't often result in immediate benefits or cost savings." There is also little incentive to create outreach and prevention programs in which benefits to the insurer may not be apparent until long after the program ends.

"Mature" managed care markets, i.e., those with a high market share, seem more committed to health assessment, outreach and education than "less developed" markets, according to some observations. Mature markets focus more on improving the overall health of their covered population since they carry the long-term financial risk for this population. In less developed markets, the primary focus is still on gaining market share and establishing stable networks. Under this paradigm, as managed care "matures" it will, theoretically, improve. However, even optimists agreed that maturity will not necessarily ensure that profits go back into research- "managed care organizations may be willing to apply new knowledge, but it is not clear what their investment in research and education will be," noted one speaker.

Presenters also distinguished between for-profit and not-for-profit managed care, emphasizing that many not-for-profit organizations are intimately involved in supporting integrated health care delivery and have strong affiliations with private medical centers. A "spirit of cooperation"-establishing community coalitions and alliances-was recommended to help fund integrated health care delivery, particularly for the underserved. Many academic medical centers are seeking partnerships with community hospitals, community-based organizations, and foundations to improve access to health services and maintain research efforts. The missing partner in most alliances, however, is managed care. Strategies need to be developed to improve collaboration with managed care organizations and encourage them to share in this funding responsibility, since they also have a stake in improving the health status of the population.

In addition, implementing measures for screening and prevention activities would provide needed data to report back to the public, who can then hold managed care organizations accountable for their policies. National organizations can assist by recommending health care guidelines, since coverage of prevention and outreach activities by insurers is typically limited to proven approaches. The reluctance of managed care organizations to invest in training and education was viewed by some as the most serious threat to cancer research, with long-term consequences for patient care. "If we don't refuel our ability to stay on the cutting edge of advances, then 10 years from now we will have fallen behind," predicted Dr. Harold Freeman, Panel Chair. The question of who will support clinical investigators remained unanswered.

Changes in the dissemination of cancer information in the context of managed care were also addressed. Representatives of the Cancer Information Service (CIS) and American Cancer Society stated that while access to information is increasing through sources such as the Internet, access to "impartial scientific information in easy-to-understand terms" is more difficult to obtain.

Cautious consumers are seeking out their own information through online databases (MEDLINE, CANCERLIT), the Physician's Data Query, and cancer discussion groups. Instead of decreasing the number of calls to public cancer information services, the opposite has occurred-more people are requesting help in understanding the complex information they are reading. More calls are also being received from consumers concerned about the quality of their cancer care, describing delays in treatment and referrals back to primary caregivers for followup. This points to additional resource needs not previously contemplated.

The managed care trend toward early discharge and outpatient care is also creating unique information needs. For example, the early discharge of mastectomy patients has increased the calls to the CIS regarding home care issues. The Panel noted that such service is really subsidizing patient care that should be paid by insurers. Another area being indirectly "subsidized" is family counseling on cancer issues.

The Panel heard moving testimony that the emphasis on "managed cost" may be occurring at the expense of quality care and further erosion of access to care for vulnerable groups such as minorities, the elderly, the poor, and the uninsured. According to one report, poor and elderly Medicaid recipients in the Southeast have experienced poorer health outcomes using health maintenance organizations than with traditional point-of-service programs. Academic health centers testified that they must continue to underwrite care for the indigent, and that these populations are virtually excluded from clinical protocols. In general, cultural factors are not being competently addressed in research, cancer care, or preventive practices. To halt the decline of patient accruals in clinical research, most experts agreed that cost sharing should occur, with managed care organizations being responsible for standard patient care costs. Consumer pressure to move managed care in this direction should be adequate, but legislation may be necessary. Mandating oversight mechanisms and information systems to ensure quality and continuity of patient care was also recommended. Federal and State governments that contract with managed care organizations should negotiate support for clinical trials.

The Panel was reminded by one of the many victims of cancer that Americans must not forget they are fighting a war with this disease-a war in which more than 1,500 lives are lost each day. We need to seek ways to ensure that the enemy is not ourselves-that evolving systems of health care delivery provide patients with the best weapons to fight their disease, provide access to the necessary tools to build upon cancer research advances, and "put the CAN into curing cancer."

The Panel will integrate the results of its four meetings assessing managed care's impact on the war against cancer, and present conclusions and recommendations to the President. An important issue will be to define the values that should be part of our health care system and articulate how these can be infused into a market-driven system. From the consumer perspective, it is still better to prevent cancer than to treat it, and measuring only cost-effectiveness will ultimately lead to distortions in the values we desire to promote. In his conclusions, Dr. Freeman recognized this, stating, "the issue of values, ethics, and morals is hard to quantify, but nothing is more important. Quality must coexist with efficiency."