Legislating Evidence-Based Cancer Care

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In 1971, President Nixon declared war on cancer. Remarkably, in a year known for growing détente with the former Soviet Union and his historic trip to China, Nixon hoped that the passage of the National Cancer Act would be viewed as “the most significant action” taken by his administration [1]. Over 30 years later, Congress is capable of making an equally historic contribution to cancer care as it considers sweeping legislation to improve cancer care.

Among a number of notable proposals introduced by Senators Feinstein [2], Brownback, and Gregg [3], is Senator Kennedy’s Quality of Care for Individuals with Cancer Act [4]. Whatever legislative compromise is reached, the Kennedy Bill has features that should be included in any initiative to enhance the care of the cancer patient and the continued translation of advances from bench to bedside and beyond into the communities where cancer patients are diagnosed and cured, palliated and comforted.

Kennedy introduced his bill at a Capitol Hill press conference last fall. With cancer survivor Lance Armstrong by his side, Kennedy noted that “our goal is to match the nation’s excellence in cancer research with state-of-the-art excellence in cancer care” [5]. This initiative would create the infrastructure so that patients and their families would maximally benefit from our investment in basic research and the coming revolution in molecular medicine.

MOVING BEYOND THE WAR ON CANCER

Passage of the Kennedy Bill would be more than a fitting complement to the advances in basic science research that followed the National Cancer Act. It would acknowledge that advances in basic science, as critical as they are, do not in themselves translate into better clinical care. Although dramatic progress has been made in the treatment of childhood leukemia, Hodgkin’s disease, and testicular cancer, the war on cancer had not, by the mid-1990s, led to the decreases in cancer mortality that were expected in 1971 [6]. Although mortality rates seem to have fallen recently for solid tumors [7], the aging of the population will increase the overall burden of cancer in our society [8].

Remarking on this tentative progress, Vincent DeVita observed that the basic science knowledge produced by the National Cancer Act has just reached a “critical mass of usable knowledge” [9]. While this may be true, the ongoing controversy about whether we have made meaningful progress in battling cancer [10] suggests that we need to do more than perpetuate the war on cancer metaphor and appreciate that it does not do justice to the complexity of comprehensive cancer care [11]. Just as global conflict may be redressed with diplomatic and/or military means, the advancement of cancer care will also occur on multiple fronts. Improved cancer care should not be confused with our growing knowledge of tumor biology or drug development for the cancer armamentarium. Instead, it is about prevention, earlier diagnosis, better organized care, and enhanced access to supportive services. And once the war has been waged, comprehensive cancer care is about marshalling the resources to rebuild a survivor’s life or comforting those who have eluded cure.

The Kennedy Bill transcends the war metaphor and suggests a more mature way to think about cancer care. It urges us to acknowledge that providing better care to patients with cancer is organizationally more complex than the waging of battle. It reminds us that good outcomes, while influenced by the quality of one’s oncologist and chemotherapy, do not rest entirely on good doctors and effective drugs. Effective care depends upon better linkages across the
continuum, the minimization of discontinuity, and the optimization of communication. An elegant cure for a treatable cancer given by a gifted practitioner will be of little value if primary care providers do not engage in timely cancer screening and a patient is referred with intractable disease.

**THE QUALITY OF CARE FOR INDIVIDUALS WITH CANCER ACT**

Through an amendment to the Public Health Service Act, the Quality of Care for Individuals with Cancer Act would improve the quality and scope of the data available to cancer care providers and lead to systemic reforms that would yield better integrated and patient-centered care. As introduced in the last Congress, the cost of implementation would have appropriated approximately $37.5 million.

The Kennedy Bill seeks to catalyze collaboration among academic medical centers and community-based organizations so as to develop “partnerships to speed the pace of improvements in the quality of cancer care.” To this end, the legislation calls for the assessment and expansion of current indicators of quality care, the bolstering of cancer registries, and the funding of demonstration projects to model the monitoring and evaluation of cancer care outcomes. State cancer registries could apply for grants to link disparate databases and develop ways to use registry information to improve practice patterns. Questions of non-cancer comorbidities, regional variation in practice patterns, and health care disparities are also identified as areas of needed study.

The Kennedy Bill would also establish a Cancer Surveillance System. This program, to be coordinated by the Centers for Disease Control and Prevention (CDC) and the National Cancer Institute (NCI), would monitor the activity of state registries and establish a national registry clearinghouse. This clearinghouse would coordinate the exchange of information among registries to ensure the timely dissemination of important epidemiological information. This Cancer Surveillance System would explore whether state registries might play a role in monitoring the quality of palliative care services. This state-based assessment of palliative care services builds upon statewide initiatives to improve palliative care that took place in the late 1990s [12].

The legislation’s most ambitious—and likely enduring—proposal is the establishment of a National Cancer Control Program. Such a program has long been in place in the World Health Organization (WHO) [13], and this initiative would give comprehensive cancer control efforts its rightful place in the Federal bureaucracy.

The National Cancer Control Program would be a joint venture led by the CDC in consultation with the Agency for Healthcare Research and Quality and the NCI. Blending the disciplines of epidemiology and health care services research, its mission would be to further refine comprehensive cancer control programs by funding innovative demonstration projects. While the funding for this program was budgeted at a modest $15 million for fiscal year 2003, recognition of the need for a National Cancer Control Program should be considered an important incremental advance.

Despite these important—and long overdue—systemic reforms, the focus of this legislation remains on the patients and families confronted with cancer. Investment in infrastructure is geared to the development of an accessible and seamless delivery system designed to optimize outcomes. This is exemplified by a proposal to provide understandable information about clinical trials to patients and families and the support of cancer survivorship programs.

The introduction of ombudsman programs to help individuals coordinate their care is also emblematic of the bill’s legislative intent. These patient advocates would help patients navigate the complex array of choices faced by those diagnosed with cancer. Navigational assistance would not be limited to questions about active treatment but also for the coordination of preventive services and palliative care.

The bill’s most notable proposal is the establishment and enhancement of both palliative and end-of-life care programs. This is especially timely given the evolution of palliative care over the past decade and its acceptance as an important clinical discipline able to foster comprehensive pain and symptom management during the entire course of illness.

The legislation would support demonstration projects that would enhance the delivery of palliative care and places a special emphasis on services for children, a group of cancer patients who are often overlooked as potential beneficiaries of humane end-of-life care. Research in palliative care has been underwritten by foundation support for the past decade, and the field is now ripe for additional Federal funding [14].

Funds would be used to further integrate palliative care into the fabric of the health care delivery and increase public awareness of palliative care services. Research would also support clinical trials related to pain and symptom management and studies to determine whether palliative care strategies designed for cancer patients might be beneficial to other populations. Grants would also support the dissemination of evidence-based information about palliative care and be used to fund pilot training programs in palliative care for a broad range of clinicians. This would help sustain and broaden educational programs in palliative care undertaken by medical societies or professional organizations often with philanthropic support [15, 16].

**ENHANCING PALLIATIVE CARE**

The most remarkable aspect of the Kennedy Bill is its sober acknowledgement of cancer death. Despite our fervent
hopes to the contrary, many cancer patients will die and require comprehensive end-of-life care. This legislation admits this difficult truth and posits an affirmative ethical obligation to ensure that dying patients and their families have access to comprehensive palliative care services. It appropriately adopts a comprehensive definition of palliative care that includes both pain and symptom management and psychosocial support. This approach is consistent with that of the WHO and others who have sought to delineate the scope of palliative care services [17-19].

More critically, this legislation squarely places palliative care into the mainstream of services utilized by cancer patients. It does not marginalize palliative care as therapies that only have value at end-of-life care but appropriately integrates these interventions into broader oncology practices. This approach is consistent with recent recommendations of the Institute of Medicine (IOM) concerning end-of-life care and palliative care for cancer patients [20, 21].

Society might prefer to deny death and invest hope in the latest drug or treatment. Senator Kennedy and cosponsor Majority Leader, cardiothoracic surgeon Dr. Bill Frist and their colleagues, however, have courageously crafted legislation that will meet the needs of cancer patients and their families, some of whom will die and suffer losses. These senators have responsibly and responsively represented their constituents. Though this legislation may not poll well, it will make an enduring impact on the lives of dying patients and their families. This is representative government at its very best.

CANCER CARE AND INCREMENTAL HEALTH CARE REFORM

Beyond the benefits that would accrue to cancer patients and their families, the Quality of Care for Individuals with Cancer Act serves an even larger purpose. It integrates the fruits of health services research into the planning of evidence-based health care reform. Lessons from such an effort should help us overcome the “quality chasm” described by the IOM and move us toward a system that fosters “continuous healing relationships” [22].

As the 108th Congress convenes, the possibility for incremental health care reform is better than at anytime since the Clinton initiative of 1994. Reform of cancer care is a worthy first step in that direction. The Kennedy Bill should be the centerpiece of any legislation designed to improve cancer care. Its bipartisan sponsorship should engender support among liberals and conservatives and the endorsement of both oncologists and heart surgeons alike.

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REFERENCES

4 Quality of Care for Individuals with Cancer Act. S. 2965, 107th Congress, 2nd Session.
The senior editors and editorial board are pleased to welcome Dr. Joseph J. Fins as the editor of the new Medical Ethics section of *The Oncologist*. 

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