Information as a "Cure" for Cancer

The National Cancer Institute (NCI) has launched a test of the interesting hypothesis that information can reduce cancer mortality in the United States. In collaboration with BRS/Saunders, a private medical data base, the cancer institute is sponsoring a new nationwide information system that will allow any library or practicing doctor with a personal computer to tap into Physician Data Query (PDQ) to get data on treatment for more than 80 types of cancer.

The cancer institute, which has been working on PDQ for several years, has had it on-line through the National Library of Medicine since March 1984. As of this month, NCI carried its experiment further when licensing agreements with BRS/Saunders were completed. Subscribers can access PDQ nearly any time, day or night.*

Cancer institute director Vincent T. DeVita, Jr., hopes that widespread use of PDQ will give community physicians information about cancer treatment that will enable them to save the lives of patients who are now dying because their doctors do not have ready access to information about new and successful therapies.

According to cancer institute figures, cancer should be curable today in 50 percent of patients with serious tumors. But to achieve and, DeVita hopes, improve on this cure rate, patients must have access to the best therapy. Developments in cancer treatment, often subtle but crucial, are occurring with unprecedented frequency; the trick is to spread the word. According to DeVita, 80 to 85 percent of cancer patients are seen by community physicians. "The greatest problem for these doctors is keeping up," he says.

PDQ offers three types of information at the push of a home computer button. First, it reports state of the art treatment regimens by tumor and stage of growth for those cancers for which an effective therapy is available. Second, PDQ contains detailed data on more than 1000 experimental treatment protocols for those tumors (still the majority) that cannot yet be cured. Third, it offers a directory listing by name, address, and phone number some 10,000 cancer specialists, along with 2000 institutions that have NCI-designated cancer centers or cancer programs approved by some medical group. For instance, the directory lists hospitals whose cancer surgery programs have been accredited by the American College of Surgeons. All of this information is arranged geographically so that a nonspecialist can easily locate an oncologist in the region for consultation or referral.

The range of information on PDQ, as DeVita describes it, is considerable. For instance, it will tell a questioner that testicular cancer, once fatal, is now nearly always curable in early stages and explain the therapy of choice. It will also report that in treating a rare melanoma of the eye, two centers with proton beam accelerators (one at Berkeley and one at the Massachusetts General Hospital) can cure the disease and save the eye. PDQ will tell an interested physician how to refer a patient with occular melanoma to one of these highly specialized, experimental programs.

PDQ is managed by a two-tiered editorial board of 72 specialists, the core of which meets at the cancer institute every month to peer-review new data as they come along and to evaluate information already on-line. It is expected that some of the information in PDQ will be so new that it will be available through the query system before it appears in a scientific journal. DeVita cites therapeutic approaches to a particular stage of Hodgkin's disease (stage 3A) as an example. Radiation has been considered the most effective way to treat these patients. However, within the past 6 months, three separate studies have come in showing that chemotherapy is equally effective. "As far as I know, there is no single scientific paper that explicitly says radiation and chemotherapy are equally effective," he told *Science*. But PDQ does.

Cancer institute officials see PDQ as the fulfillment of a mandate given them in the National Cancer Act of 1971, the legislation that launched the "war on cancer" and called for the transmission of data to practicing physicians "insofar as feasible." At the time, there were fewer than 100 medical oncologists in the country and only 300 radiation therapists who specialized in cancer. Today, 3000 physicians are Board-certified oncologists and the number of certified cancer radiologists is close to 2000. The number of NCI cancer centers has grown from three to 53. Effective therapy has been discovered for tumors that formerly were not treatable. And the home computer has arrived. "What we're doing now with PDQ simply would not have been feasible before," DeVita observes. The question now is whether physicians will use it. Says DeVita, if patients know about it, they will.

PDQ was not developed without controversy. One was over access. One school of thought held that PDQ should be available directly to patients. Others argued that the data would be presented in too much technical detail, that they could confuse, or, in the case of tumors with a poor prognosis, unduly frighten patients. The latter group prevailed, although the public has access to an NCI information line.†

Another source of contention is the directory of physicians. The cancer institute's plan to list by name and phone number those doctors who spend most of their time taking care of cancer patients angered the American Medical Association (AMA), which opposes such lists and also vehemently objected to the idea of a government agency in effect certifying certain physicians. In an effort to sidestep the appearance of being a certifying agency, the NCI decided merely to reproduce lists of doctors already compiled from medical specialty groups including the American Society of Clinical Oncology, the American Society of Hematology, the Society of Gynecologic Oncologists, and so on. The AMA remains firm in its opposition. The NCI remains convinced that PDQ would not be worth much if a community physician could not use it for a real-life referral. And the two have "agreed to disagree."

The ultimate value of this experiment in information-sharing will be indications that more patients with curable cancers are being successfully treated. An evaluation protocol is in place but it likely will be several years before anyone knows whether PDQ is lifesaving.

—BARBARA J. CULLITON

*PDQ is available to subscribers to the BRS/Saunders' COLLEAGUE system. For information, call 1-800-468-0908, or write to PDQ, R. A. Bloch Building, Rm 105, Bethesda, Maryland 20205.

†Individuals may call 1-800-4-CANCER.