Commentary (Fesen): NCI's Cancer Information Systems-Bringing Medical Knowledge to Clinicians

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Hubbard, Martin, and Thurn describe PDQ, CANCERLIT, and other International Cancer Information Center (ICIC) programs that bring cancer information to health professionals, patients, and policy makers. PDQ (Physician Data Query), the cancer information "knowledge base" of the ICIC includes information on cancer treatment, screening, and prevention, as well as cancer research protocols and a directory of physicians. The focus of the article is on content of, and access to, PDQ as well as other ICIC programs.

PDQ as a knowledge base is unmatched in other medical disciplines, and hence is the envy of other specialties. Similar programs do not exist for cardiology or gerontology, for example. It is responsible for marked improvements in information dissemination to both patients and physicians. The efforts of the NCI, the ICIC, and Hubbard to further improve PDQ content as well as its rapid dissemination are applauded. However, rapid change in oncology, medicine, and health care policy, as well as the great need for cancer information, indicates that even these tremendous efforts are unfinished.

PDQ Content

Recruiting outside medical and cancer treatment organizations with common goals into the PDQ effort would create a more clinically useful database while avoiding costly duplication of services. For example, only certain experimental drugs are described in PDQ. Incorporation of both patient and physician-oriented chemotherapy drug information from one of the available drug information compendium would give users quick access to important drug information. Such integration of efforts across disciplines and organizations would give greatly expanded services at minimal added cost.

Another area where integration of services and efforts is needed is in the supportive care section of PDQ. Hospice services are recognized by physicians as well as by Medicare as standard care for many terminal cancer patients. Description of hospice treatment goals and philosophy for terminal cancer patients is absent from PDQ. National hospice organizations could be involved in introduction of this idea into PDQ. Supportive care treatment options, including hospice care, are important to many patients who, as the ultimate decision makers, should be made aware of all of their treatment options. Listing hospice as a "treatment option" for patients with relapsed and poorly responsive tumors would give patients a complete listing of their options, including the permission to stop active treatment.

The most common question I am asked by patients after treatment options are discussed is, "Does Medicare pay for this?" PDQ information includes a disclaimer that the information in PDQ cannot be used for reimbursement determinations. The disparate advisory boards within PDQ, the FDA, and HCFA (all sections of the US Department of Health and Human Services) should be integrated into a common voice, such that recommendations regarding cancer treatment advised by one arm are reimbursed and endorsed by the others. By not addressing reimbursement issues, PDQ assumes a more distanced academic tone inconsistent with recent health care debates that take a more realistic and global view of the effect of treatment recommendations on health care expenses. It is inconsistent if PDQ advocates a treatment if Medicare does not reimburse for it.

One omission in the Hubbard et al article was the deletion this year of the "standard protocol" section of PDQ. In this section, commonly used protocols such as MOPP/ABV or 5-FU/leucovorin were listed, complete with dose modifications, etc. Confusion about the term "protocol" led some PDQ users to believe that patients could be "enrolled" on such a standard protocol. Reluctance to list
treatments of limited efficacy, such as 5-FU/leucovorin, as "standard" also contributed to the
decision to delete this section. Such a compilation of "standard" protocol was useful, and served to
reflect the best available standard care. Community oncologists recognize all too well the
inadequacy of many of our treatments.
Listing of protocols is a fundamental and extremely useful service of PDQ. NCI and approved non-NCI
protocols are listed. Non-NCI protocols are listed after passing a thorough review process looking at
study design, patient risk, entry criteria, etc. While appreciating well-meaning efforts to ensure
appropriate study design and patient protection, censoring protocols to those approved by a board is
inconsistent with the "Bringing Medical Knowledge to the Decision-Makers" theme of the article.
Listing all submitted protocols, perhaps as "approved" and "unapproved," would bring even more
information to oncologists, and would help them decide which protocols to recommend to their
patients.

**PDQ Access**
Currently, patients primarily receive PDQ information through their physician's office. Only the most
highly medically sophisticated patients are aware of PDQ before they see their oncologist. As the
ultimate decision makers in the cancer treatment process, greater efforts should be made to make
the general public aware of the PDQ knowledge base. Local, state, and national cancer organizations
or support groups, as well as public libraries and local hospitals, could be recruited in the efforts to
more broadly familiarize the general public with PDQ.

**Summary**
In summary, efforts to improve and critique PDQ and other ICIC cancer information efforts are
healthy. For physicians and policy makers, PDQ access has been made even easier by the
Information Associates program. Access efforts should be focused even more on direct patient
availability issues. Content of PDQ could be mainstreamed by joining efforts with other cancer
organizations. Reimbursement issues will be essential to address and may even be required in the
future.

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