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NCCN Guidelines Then and Now

I recently read a news story from a 1996 issue of JNCI (J Natl Cancer Inst 1996; 88:488–490) that discussed the debut of a then-new product: the NCCN Clinical Practice Guidelines in Oncology. That news story cited the main challenges facing the program as 1) integrating the guidelines into practice and 2) collecting data and evaluating the guidelines’ impact on practice and patient outcomes. A third challenge was gaining employer and payer acceptance. As we approach the NCCN’s 13th Annual Conference, it’s interesting to see where we are in facing these 3 challenges and looking at the additional challenges that have arisen in the intervening years.

Looking back, I think these expectations were right on target. What the writer did not foresee was the degree to which electronic methods of communication and informatics initiatives would change how clinical information is distributed and used. At first, the NCCN guidelines were published only as paper-based proceedings of our annual meeting, with only the guidelines presented at the meeting published in a given year. Now the original 7 guidelines have been updated (at least annually and usually more often) for 13 years. In addition, they have been joined by more than 35 additional guidelines, also aggressively updated, and all published continuously on the Internet.

The ease of Web publication has certainly changed expectations, with the anticipation that standard-changing new data can and will be incorporated into guidelines in almost real time. Similarly, newer derivatives of the guidelines, such as the NCCN Biologics Compendium as its standard for coverage policy.

This level of updating requires a huge effort, and we currently work with more than 800 volunteer faculty members from our 21 member institutions to achieve it. In the early days, whether faculty members could agree on treatment recommendations was not clear, nor did NCCN’s founders know if panel members would have the dedication to perform revisions year after year. We are continually impressed with the enthusiasm and dedication of these experts, which seems to grow as the influence of these tools increases.

As to integration of the guidelines into practice, I am pleased to say that I now have difficulty finding an oncology professional who is not aware of them. The volume of guidelines discussion at major medical meetings and citations in the literature, as well as the number of requests we get to submit data to the panels, all indicate the impact the guidelines have. Also, NCCN has been approached by several developers of electronic medical records and decision support, who are interested in using the guidelines more and more.

Evaluating patterns of care and concordance with the guidelines has also become a reality. Under the leadership of Jane Weeks, MD, databases in breast, colorectal, non-small cell lung, and ovarian cancers, and non-Hodgkin’s lymphoma were developed. For example, more than 35,000 breast cancer patients are currently being followed up longitudinally from initial presentation at an NCCN center. Exhaustive reports on concordance are provided to participating centers annually, permitting each center to compare its performance with that of the network as a whole. Quality measures have also been developed using known levels of guideline adherence.

And payors are increasingly accepting NCCN information as standard of care. In January United Health Care announced that it has selected the NCCN Drugs and Biologics Compendium as its standard for coverage policy.

Taking stock of the past 13 years shows that the NCCN Clinical Practice Guidelines in Oncology and other products have succeeded in meeting those early challenges. We look forward to continuing to build on that success as we pursue our mission of improving patient care.

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