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The ideas and viewpoints expressed in this commentary are those of the author and do not necessarily represent any policy, position, or program of the NCCN.

Informing Patients: Translating the NCCN Guidelines

Health care professionals are accustomed to using clinical practice guidelines to elucidate questions regarding cancer and its treatment. In a recent survey by the Association of Community Cancer Centers, 94% of physicians indicated that they refer to clinical practice guidelines when engaged in direct patient care. Since 1996, the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines) have been recognized as an authoritative source of evidence-based recommendations for managing the vast majority of cancers. The NCCN Guidelines recommendations represent a distillation of up-to-date evidence evaluated by expert subspecialty clinicians organized into flow charts that follow the clinical decision-making process. Clinicians can go to the NCCN Guidelines to find out the current thinking of expert clinicians on a wide variety of issues and to find the information they need quickly and efficiently.

For someone diagnosed with cancer, the landscape looks different. The world changes dramatically. A body that has served well for decades suddenly seems far less reliable, and survival itself may be in question. Information that was at most peripheral to daily concerns suddenly takes on tremendous importance. The vocabulary is unfamiliar, almost a foreign language to some patients. What type of cancer is it? What is a primary site? Is it *really* the same type of cancer when it has spread to the lungs or the bones?

Decisions are needed regarding workup, primary therapy, and whether one treatment is better than the others. Decisions are also needed on where to be treated and by whom, and how to find a specialist and what kind, among many others. Patients are aware that some of these decisions might mean life or death, but, without knowledge and experience, they may not know which ones. It feels like an emergency. Surely there must be somewhere to get answers.

Patients Seek Information

The popular press writes frequently about new advances in cancer treatment; however, the descriptions often lack critical appraisal of their relative benefits and risks. In addition, the question of which specific patient subsets the new treatments are appropriate for is rarely even touched on.

Similarly, although the Internet includes many sources of cancer information, some are excellent while others are questionable. In recent years, clinicians have become accustomed to having patients arrive with reams of paper with information that may or may not be relevant. Increasing amounts of time are required to evaluate and explain the information.

Often, patients have their hopes raised by reports of breakthroughs and then dashed when their doctors explain why they are not right for them.

Scientifically Accurate Answers for Patients

Health care professionals, far more knowledgeable about the procedures, tests, and treatments used to manage cancer, have their knowledge supplemented by guidelines. Clinicians may wish for more complete, accurate, and thoroughly vetted patient information that can provide reliable evaluation of cancer management issues. Fortunately, patient versions of the same NCCN Guidelines clinicians use are now

becoming available to and for patients, as the NCCN recently began translating the NCCN Guidelines into patient-friendly language.

Although still quite technical in their approach, the NCCN Guidelines for Patients provide background information about the individual disease site, its diagnosis and evaluation, staging, and treatment options that is written for people with cancer and their families. This information can be used to help to understand the decisions that are outlined in the treatment pathways. Using the NCCN Guidelines for Patients, a patient can follow along with their physician on the same pathway, which allows people with cancer to put their situation in the context of the whole disease.

As of publication, 6 NCCN Guidelines for Patients are available on the NCCN Web site for patients, NCCN.com. NCCN plans to continue the development of these Guidelines for Patients in several directions simultaneously. First, more disease sites will be added. Second, more illustrations will be added to help patients understand their disease and see photographs of actual treatment settings so that they are more familiar when first seen “for real.” Third, the language is being simplified further to make the guidelines accessible to larger patient populations. And, finally, additional topics like obtaining second opinions and end of life care will be added.

Although the NCCN Guidelines for Patients will probably always require some basic knowledge of cancer and its treatment to be most helpful, NCCN hopes and believes they add not only to the patients’ knowledge base, but also to the armamentarium used by clinicians seeking ways to provide their patients with more information about their cancer care.