NCCN Guidelines and the International Community

NCCN has developed NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines) for the treatment of cancer, management of complications, and screening. The NCCN Guidelines, regularly updated, are a fusion of scientific data and expert opinion from panels composed of oncology professionals from NCCN member institutions. Over time, these guidelines have become more and more accepted by the oncology community in the United States. They are also extensively used internationally. As reported by William T. McGivney, PhD, Chief Executive Officer of NCCN, the NCCN Guidelines also “have been requested by cancer care professionals in more than 115 countries.”

Furthermore, the 2009 NCCN Annual Report notes that 44% of all registered users are outside the United States. In 2009, NCCN approved adapted China editions of 10 different Guidelines for the management of common cancers, and the translation of NCCN Guidelines into Japanese is currently in progress. In 2009, NCCN Guidelines programs were held in Korea, United Arab Emirates, Japan (in 2 cities), and China (in 3 cities).

Thus, NCCN Guidelines are obviously filling a need internationally. The volume of data, wealth of new information, and deluge of new therapeutic agents is daunting. The fear, felt years ago, that a small group of cancer centers would dictate how cancer treatment should be managed has been replaced by acceptance of the need for a systematic way of approaching a diverse group of related diseases.

Challenges in Translation

Still, it is not likely that a single group of guidelines, however carefully prepared or regularly updated, will serve the needs of all parts of the world equally. According to the Center for Medicare & Medicaid Services (CMS), the United States national health expenditure in 2009 was $8086 per person, more than 2 orders of magnitude higher than some countries. Certainly, economic verities are such that the use of a single expensive drug to extend survival by a few months cannot trump the need for basic health care needs in parts of the world. In addition, some cancers common in Western societies are less prevalent in other societies. Melding scientific data, expert opinion, genetic variability, economic reality, and conflicting needs in countries of disparate resources and priorities will be a continuing challenge. Thus, as NCCN Guidelines are used more and more, it will be important to develop ways to effectively adapt them without straying from their basic intent.

One Good Start

In August of 2010, a conference entitled, “Câncer de Mama, ano 5” was held in Gramado, Brazil, sponsored by Grupo Latino Americano de Investigação Clínica em Oncologia (GLICO) and coordinated by Carlos H. Barrios, MD, and Antonio Frasson, MD, PhD. Advances in the management of breast cancer were highlighted, and the meeting was attended by physicians from 11 countries in Central and South America. During this meeting, 2 simultaneous discussion groups co-sponsored by GLICO and NCCN were held with the intent of reviewing NCCN Guidelines on lung and breast cancers, focusing on Latin American needs. Dr. David Ettenger from Johns Hopkins worked with the lung cancer group, and I was able to participate in the discussion of the breast cancer group.
The groups had thoroughly and carefully reviewed the relevant NCCN Guidelines and were well versed in the details. The goal was to determine if the NCCN Guidelines could and should be adapted to special circumstances in Latin America. After reviewing how NCCN Guidelines are created and updated, physicians representing a cross section of Central and South America suggested potential modifications appropriate for this vast region.

This work in progress represents just a first step in meeting the needs of cancer patients in Latin America. Any changes will be reviewed and vetted by relevant NCCN Panels before being finalized. However, this group of professionals was clear in the intent to improve care for the patients they serve; their resolve and dedication was impressive and laudable.

As perhaps expected, the economics of health care and the availability of technology were 2 challenges that came to the fore in these discussions. The political and economic circumstances in different countries within Latin America present difficult challenges in providing care for which no easy solutions are available.

Worth the Discussion?

Although the NCCN Guidelines process is now well established, some may question their use internationally, especially in light of these challenges. After all, even within countries, each individual patient has his or her own set of circumstances, comorbidities, beliefs, and needs. It’s important to remember that guidelines do not supplant the important human interaction of physician and patient. They are correctly viewed as signposts to lead those who care for cancer patients down well-traveled paths. As noted by John H. Powers, “guidelines may provide caregivers with potential answers to clinical questions, but caregivers must still generate the right questions by history taking and performing physical examinations.”

There will always be a need for wise, skillful, and thoughtful physicians who consider all aspects of the individual and illness. Guidelines are guidelines—not rules to be slavishly followed despite context and circumstance. To me, this wise statement of James Reinertsen exemplifies the complementary role of guidelines and physicians:

Perhaps it would help if we thought of guidelines as jazz scores. As practitioners, we work from a basic chord structure and melody line (clinical science) with a great deal of latitude for improvisation (the art of medicine). It’s cookbook medicine. Yes, guidelines are something like a cookbook. However, all great chefs and expert pilots use cookbooks and checklists, and diners and flyers are grateful that their experiences are not created entirely from scratch.

Ultimately, thoughtful dialogues, such as occurred at these meetings, may spur review of the needs of cancer patients in these nations. The progress and commitment of groups like GLICO, will continue to build a foundation and framework for the care of cancer patients worldwide.

References