Statements from the President's Cancer Panel

Meeting

Decision Making Based on Quality of Care Guidelines and Their Impact

What are guidelines? How should they be used by health practitioners, third-party payers, consumers, and others? How can guidelines help define, effect, and measure quality of care? How can they expand the ability to apply better care to all segments of the population?

Philosophical debate and pragmatic discussion joined hands in testimony to the President's Cancer Panel meeting on the role and impact of guidelines in standardizing and improving the quality of cancer care for Americans. The meeting, hosted by the Roswell Park Cancer Institute in Buffalo, New York, was the third and final meeting in a series designed to address quality of cancer care and quality of life through dialogue between presenters, the Panel, and members of the public.

If guidelines are to be used to establish standards of care, the goals for setting such standards must be examined. Such goals may include directing patients to the best quality care, to care that provides the best "value," or to care that will be reimbursed by insurers. Therefore, when relying on guidelines, who generated those guidelines and for what purpose must be considered.

Physicians are still perceived as the best arbiters of quality in cancer care, but in the current health care system, they are often called upon to make recommendations based on the best economic health care value for the patient, or based on what is clinically accepted as standard care versus what may be qualitatively the optimum medical care available to an individual patient. These recommendations also may conflict with individual patients' perceptions or expectations of quality cancer care.

The meaning of "value" in cancer care was discussed. The economic definition of value relates to delivering the greatest health care benefit at a reasonable cost. But even this definition must be viewed from different perspectives. It becomes a question of delivering the best possible and perhaps more costly care to an individual versus the cost of affording the greatest access to a certain standard of care for an entire population. Who should make these decisions? How are these concerns taken into account when we attempt to develop or evaluate guidelines? These questions are largely unanswered.

References were repeatedly made to developing "evidence-based" guidelines; however, the definition of evidence varied. The "gold standard" has been randomized clinical trials, but this level of evidence is not widely available. Testimony indicated that guidelines have evolved based on a broad range of considerations: from randomized clinical trials; from published expert consensus; from accepted experience of the medical community; and from informal compilations of local "best practices." They have been further tempered by the need to seek a balance between

universal or national guidelines to care and guidelines customized to reflect the needs of specific populations or cultures.

Since consumers are the ultimate recipients of care, it was urged that more consumer and patient input be included in guideline development processes, that separate "consumer-friendly" versions of guidelines be made available in parallel with health practice versions, and that guidelines explicitly require patient education and consumer involvement in choices regarding care. It was also recommended that cancer care guidelines explicitly incorporate clinical trials as an avenue for care, particularly when conflicting evidence over treatment options exists, but guidelines should not be permitted to create barriers to the continued evolution of the quality of cancer care.

Despite the complexities involved in guideline development, the real challenge appears to be implementation. The Panel heard that dissemination alone is not adequate to change thought processes and actions. Multiple strategies are needed to create an environment in which guidelines can be used to improve delivery of care, and the impact of guidelines in improving quality of care should be evaluated.

The Panel learned that more organizations are moving toward "performance measurement" and collection of practice outcome data that provide feedback to individuals and institutions on the quality of care delivered. However, how to collect meaningful data in a standardized manner across institutions, how to obtain the cooperation of providers and institutions, and how to assure that data are not misused are among the challenges remaining to be faced.

Clearly, the development of cancer care guidelines is proliferating among Federal and non-Federal organizations. This proliferation of both the sponsors for and the numbers of guidelines, as well as the variations among them, is creating a dilemma for patients and physicians. Attempts at coordination for developing and implementing guidelines are only now beginning. As this process moves forward and guidelines become equated with standards of quality care, we must remain focused on the ultimate, larger goal-that is, improving the quality of cancer care not just for some Americans, but for all Americans.