

# Statements from the President's Cancer Panel Meeting

## *Defining Quality for Cancer Care*

What is "quality" cancer care? How do we measure quality across the spectrum of cancer prevention, diagnosis, therapy, and palliation? It may be as simple as one speaker's reference to bringing "the right care, to the right people, at the right time, at the right price, to achieve the best outcomes." To explore this issue, the President's Cancer Panel, charged with monitoring the National Cancer Program, invited expert testimony on quality of cancer care issues at a meeting hosted by the Jonsson Comprehensive Cancer Center, University of California at Los Angeles. Future meetings will explore quality of life and survivorship and the use of guidelines in delivering "quality" care.

What are indicators of quality? What do people care about? Definitions and standards of quality inevitably vary based on individual viewpoints (i.e., patient, physician, insurer). Dr. Harold Freeman, Chair of the Panel, described this as one of the challenges to the Panel-- "bringing these various perspectives together in a way that makes sense to the public." Presenters agreed that relying on evidence-based guidelines in rendering care is preferable, but raises difficult questions of cost and timeliness. For example, "who should pay" for creating better, more uniform data collection methods to assess quality and inform standards of care? The risks and benefits of waiting for clinically proven standards versus accepting standards of care based on medical consensus and years of practice must also be weighed into the "quality of care" equation.

The Panel questioned how "quality" can be assessed and improved on a continuing basis. One way is evaluating medical outcomes (i.e., five-year survival rates), with the understanding that outcomes achieved in clinical studies (with optimal conditions and adherence to protocols) are not typically achieved in the "real world." Measuring differences between "trial efficacy" and "real world effectiveness" can improve quality when efforts are made to bring the two outcomes closer together. However, quality assessment must also evaluate structures (communities, hospitals, providers), processes (how care is delivered), and other outcomes such as functionality, quality of life, and satisfaction with care. Overall, better systems are needed to capture and standardize patient, process, and outcome information related to measuring quality of care.

Where does investigational therapy fit into the definition of quality care? Many believe "new is better" and that no costs should be spared in treating life-threatening illness. Access to investigational therapies remains controversial--one side viewing them as unproved and unadvised, and the other calling them "state-of-the-art" and, often, a "last chance" for recovery. In a health care delivery system increasingly focused on cost, investigational therapies provided in the context of determining efficacy and therapeutic value are the most likely to be supported by third party

payers.

The delivery of the "right care" is often dependent on the effectiveness of patient-physician communications upon which decisions are based. Patients and families must become more active participants in their care. "There is no longer room for paternalism," one presenter stated. We must enable clinicians to better understand what information patients need and value, how to counsel about risk, and how to promote shared decision making.

Tailoring cancer care to the "right people" is another critical aspect of quality. Research to define standards of care and assess the risks and benefits associated with specific types of care may not be generalizable to all subgroups within a study population, i.e., subgroups whose numbers are too small to significantly impact study outcomes, yet who clearly experience different health outcomes. While knowledge of cancer risk is increasing, little is known about the process of communicating this information in ways that will effect behavior change, particularly for diverse populations. Current research and clinical care focus on providing cognitive information, which may not be as effective as approaches that identify and capitalize on personal, cultural, or community values.

Quality of life issues must always be considered in decisions regarding cancer care. A clear responsibility of physicians is to thoroughly explain the effects of treatment--biological and functional. The balance of quality of life against care options must be made by patients themselves; their perception and tolerance of complications and resulting health burdens is intensely personal and naturally different from that of physicians.

Speakers describe quality of life as a continuum--from the time of diagnosis until death. For cancer survivors, the measure of "five-year survival" is short; they define survivorship as "remaining life." Quality cancer care for survivors includes preventing disease recurrence, minimizing future treatment- and disease-associated complications, controlling pain, and maintaining or improving functionality. The issues associated with long-term care and follow up for cancer survivors have not received adequate attention. Ironically, as the war against cancer is won, the number of cancer survivors will grow. To meet their needs, new strategies to improve long-term care must to be developed.

Finally, defining standards for diagnostic quality is essential. The precision and quality of screening technologies and cancer pathology define a patient's diagnosis and fundamentally influence choices regarding treatment and care. Stringent testing and quality assurance processes already appear to exist; however, there is some concern that pressures to reduce costs may place these quality standards at risk.

Defining "quality" cancer care is a critical issue for the National Cancer Program. It is a complex interplay of understanding what standards of care should exist, when they should apply, and how they should impact the delivery of care. Equally

important, however, is assuring that the care we ultimately define as "quality" cancer care is made available and accessible to all populations.