Statements from the President's Cancer Panel

Meeting

Quality of Life and Survivorship

June 2, 1998

More than 200 people, many cancer survivors, came to listen and participate as the President's Cancer Panel heard testimony on quality-of-life and survivorship issues in relation to cancer care. Hosted by the Yale Comprehensive Cancer Center, this was the second in a series of three meetings examining quality of cancer care issues. The message to the Panel was clear-quality of life, survivorship, and end-of-life issues have not been adequately addressed as part of a continuum of care. "I am impressed with the amount of research that needs to be done in this area," remarked Dr. Harold Freeman, Chair of the Panel, promising to report the Panel's findings to the President.

The "Survivorship" movement and its evolving research and health care agenda, in many ways, reflects the success of the National Cancer Program over the past 26 years: cancer is no longer a death sentence. Dr. Vincent DeVita, Director of the Yale Cancer Center and former Director of the National Cancer Institute (NCI) (1980-88), reminded the audience that the purpose of the National Cancer Act, passed in 1971, was to move beyond basic research to application of research results in order to increase the number of cancer survivors and the quality of their survival. The funding for application of research made possible by the Act is responsible for the growing number and diversity of survivors-approximately 8.25 million today. Dr. DeVita reminded the Panel of its responsibility under the Act to maintain a balance between research and application in order to continue such progress.

As progress in developing new cancer treatments continues, cancer survivors are demanding improved quality of life-from diagnosis through the end of life; it is not enough to simply survive. Survivors want to know how being diagnosed with cancer and undergoing treatment will impact them physically, psychologically, socially, and spiritually, both now and in the future, in order to make the best personal decisions regarding their well-being.

Existing studies show that there are long-term effects on the quality of life that cancer survivors can expect. Such quality-of-life issues include:

- Physical risks of complications, such as disease recurrence, secondary cancer, cognitive impairment, sexual dysfunction, and fatigue
- Psychological risks, including anxiety and depression; social consequences in the workplace, at home, and among friends
- Economic burdens associated with treatment and care. However, available data, particularly relating to quality of life for adult cancer survivors, are limited. A research strategy is clearly needed in this area.

The prospect of being at risk for additional cancers is one of the more frightening outcomes of being a survivor. It was strongly suggested that risks of secondary cancers be quantified in ways that will lead to opportunities for surveillance and prevention among survivors. Psychological effects-fear of recurrence, anxiety, distress associated with anniversary of diagnosis-debilitate many survivors. A plea was made to study the prevalence of such effects on survivors, and develop assistive interventions. The continuing physical issues that many survivors face requires an increased focus on rehabilitation. Clearly, survivors' needs are multidimensional, raising the question of where cancer survivors should go for long-term surveillance and followup care-primary caregiver, oncologist, or other health care provider.

Data were presented from pediatric studies that began 25 years ago incorporating long-term followup and surveillance to determine late effects of treatment and disease. Younger age and the fact that average survival for children is 60 years (versus 15 for adults) has prompted research to minimize the effects of treatment on growth, development, and reproduction. Many cases were presented in which interventions and therapeutic modifications have been developed as a result of unacceptable treatment side effects (e.g., significant height loss, late cardiac disease). Progress in reducing incidence of secondary cancers has been significant. However, it was urged that more research be supported to predict the effects of treatments, particularly interactions of treatments with predisposing conditions.

End-of-life care was introduced as a survivors' issue, given that approximately half of those diagnosed with cancer eventually die of their disease. Cancer research and care traditionally have focused first on cure and only now are coming to terms with needs for better palliation and hospice care in the continuum of cancer care, research, and training. Strategies to control pain, manage symptoms, and help survivors and families plan and bring closure to life are vital.

Recommendations made to the Panel were to:

- Include long-term followup of cancer survivors in clinical protocols
- Develop "centers of excellence" in palliative care to serve as the leadership for research in this area
- Promote interdisciplinary research and the development of guidelines for long-term care, rehabilitation, and followup
- Identify opportunities for interventions that can ameliorate negative effects of treatment and improve quality of life
- Include palliative care, hospice care, and related medical education and training as research issues associated with cancer survivorship.

A new phase in the war on cancer has been entered. In the past, researchers have concentrated on developing treatments, some of which are very effective. However, quality of life issues for survivors have not been well addressed. "As a Nation, we have made great progress in improving survival," concluded Dr. Freeman, "but it is now time to turn our attention to improving the quality of that survival."