

August 8, 2006

Patricia Maryland, PhD, Chair  
Citizens' Health Care Working Group  
7201 Wisconsin Avenue  
Suite 575  
Bethesda, MD 20814

Dear Dr. Maryland,

On behalf of the End-of-Life Nursing Education Consortium (ELNEC), we congratulate the Citizens' Health Care Working Group for their work on the Interim Recommendations on how to improve health care for all Americans. Your efforts to conduct community meetings, to review the public opinion polls, to read internet responses, and to review commentaries from thousands of Americans are admirable. We appreciate this opportunity to make comments about these recommendations.

The ELNEC project is a national education initiative to improve end-of-life care in the United States. Since its inception in 2000, over 2,880 nurses, from every state in the Union and the District of Columbia, have attended a national ELNEC train-the-trainer course. These nurses have returned to their universities and clinical institutions to train thousands of their colleagues in excellent end-of-life/palliative care. The project provides training for undergraduate and graduate nursing faculty, CE providers, staff development educators, pediatric and oncology-specialty nurses. We are currently developing two new ELNEC curriculums to meet the unique needs of critical care and geriatric nurses.

In reviewing the recommendations, we would like to make the following comments:

- Beginning with the final recommendation (#6), we applaud your efforts to include palliative and hospice care. While this recommendation is good, we would suggest that issues related to end-of-life/palliative care be woven throughout the entire recommendations, so that both are seen as more "mainstream" and its attributes would become an integral concept of quality health care throughout the life span. Americans deny death, believing that medical science can cure any patient. Death often is seen as a failure of the health care system rather than a natural aspect of life. As the recommendations stand now, 'Palliative care, hospice care and other end-of-life services' are "tacked-on" at the end of these recommendations. Below are some examples of ways end-of-life/palliative care can be embedded throughout the recommendations:



- “Values & Principles” (p. 6)—“Healthcare encompasses wellness, preventive services, and treatment and management of health problems.” This implies more of an emphasis on curative measures. What about Americans that can not be cured? What about those who will never be well? And what about those who have no further curative treatments available to them? Certainly, palliative care/end-of-life services should be more emphasized here.
- “Recommendation #1 (p. 8): In regards to “core health care services,” this should be specifically outlined to include wellness, preventive services, treatment and management of health problems, AND palliative care at the end of life.
- Recommendation #2 (p.9): “Health is defined to include physical, mental, and dental health.” Again, this is focused on curative care. What services are available to people once their health is deteriorating? While it is mentioned that “the set of core health services will go across the continuum of care throughout the life span,” and since the end of the life span occurs with death, then attention must be given to Americans and their families experiencing end-of-life issues.
- Recommendation #5 (p.10): In relation to promoting efforts to improve quality of care and efficiency, we would recommend that you reference the recent Dartmouth Report (<http://www.dartmouthatlas.org>) and also review the National Consensus Projects’ *Clinical Practice Guidelines for Quality Palliative Care* ([www.nationalconsensusproject.org](http://www.nationalconsensusproject.org)). There are numerous studies that show that excellent palliative care reduces healthcare costs, by decreasing critical care and emergency room usage and diminishing length of stays in acute care facilities. Besides reducing costs, palliative care also improves pain and symptom management, and therefore, increases quality of life.
- Recommendation #6 (p. 11): In providing excellent end of life care, the plan must be interdisciplinary in its approach. An emphasis must be placed on educating all healthcare providers in end-of-life/palliative care and should be viewed as an essential competency. Staff can not practice what they have not been taught. In addition, Americans over the age of 85 are in the fastest growing population sector. Many of these elderly will live with progressive and eventual fatal illness, which generally is prolonged and marked by functional dependency on others. By 2035, older adults will represent 25 percent of the U.S. population. Education and training of interdisciplinary staff in nursing homes, long-term care facilities, skilled nursing facilities, etc. must be a priority in order for older Americans to receive the dignified care they deserve at the end of their lives. At the other end of the life span, attention and resources need to be provided to the 53,000 American children, between the ages of 0-19 years who die annually. It is estimated that 1 million children in the U.S. (10%) live with a serious, chronic medical condition. Nearly 900,000 “birth tragedies” per year include 800,000 miscarriages, 33,000 stillbirths, and 19,000 neonatal deaths. These children and their families are in great need of end-of-life/palliative care services during this very unnatural time of death.

Again, on behalf of the ELNEC Project, we thank-you for the opportunity to respond to these recommendations. Our best wishes to you and the other members of the working group as you review the many recommendations that will be submitted.

Sincerely,

Betty Ferrell, PhD, RN, FAAN  
Principal Investigator  
ELNEC Project