

DEPARTMENT OF HEALTH AND HUMAN SERVICES
NATIONAL INSTITUTES OF HEALTH

Fiscal Year 2003 Budget Request

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DEPARTMENT OF HEALTH AND HUMAN SERVICES

Statement by

Dr. Patricia A. Grady
Director, National Institute of Nursing Research

on the

Fiscal Year 2003 President's Budget Request
for the National Institute of Nursing Research

Mr. Chairman and Members of the Committee:

I am pleased to present the President's budget request for the National Institute of Nursing Research for FY 2003, a sum of \$130,809,000, which reflects an increase of \$10,058,000 over the comparable Fiscal Year 2002 appropriation.

For over a century, the nurse's role in care of the sick has been well known, especially in times of war or disasters. What is also important in this new century is the role of nurse as scientist – bringing to the scientific process an additional perspective critical to health, examples of which will be highlighted today. Our science is young, yet it is already making innovative changes to practice. These contributions were evident as NINR celebrated its 15th anniversary at the National Institutes of Health with a scientific symposium that featured nursing research programs of excellence.

The nursing shortage, however, which is capturing national attention, is emerging just when challenges to the healthcare system are increasing. Therefore, it is critical that nursing research produce results that improve health and quality of life for the American people. Innovative strategies to address these challenges must be identified, and they must be scientifically tested.

RESEARCH TO HELP CAREGIVERS

Major challenges for healthcare are the increase in age of our population, the increase in chronic illness, and the earlier discharge of patients from hospitals, which, taken together, have created a greater need for informal caregivers. These caregivers are generally family members, friends, or neighbors. According to the 1997 National Caregiver Survey by the AARP, more than 22 million adults are informal caregivers to ill or fragile Americans over 50 years of age. A study of informal caregivers, published in 1999 in *Health Affairs*, indicates that most caregivers are middle-aged, married women, almost half of whom have young children. They provide most of the long-term care in our country, yet the economic value of their services, estimated at \$196 billion in 1997, is not included in cost of illness figures. The healthcare system, in effect, depends on their collective assistance. Research to address caregiver issues is critical at this important juncture.

In addressing these issues, nursing research has focused on helping caregivers avoid or reduce their burdens, including stress, especially related to chronic illnesses, such as dementia, emphysema, and congestive heart failure. Caregivers must manage disruptive behaviors, including wandering, aggression, and sleep-wake disturbances, and they may be required to administer medication and use unfamiliar equipment, such as suctioning devices and ventilators. NINR-supported research also identifies caregiver techniques to improve their own health and quality of life.

Although subgroups of caregivers characterize their situation as a positive experience, there is also a high incidence of stress among caregivers that can lead to depression, physical illness, and increased mortality. A recently published study of a community-based 14-hour training program for caregivers, held during a two-week period, found that three months after the training, 25 percent of participants reported lower levels of depression, 28 percent reported improvement in behavioral problems of their care recipients, and 9 percent indicated that they felt less burdened. This brief

intervention provided caregivers with information and practical skills for dealing with dementia, and ways to improve confidence, coping skills, and communication. The results are illustrative of the possibilities of using coaching and teaching to reduce the negative effects of caregiving. Further research is needed to identify techniques that work best – for example, those that can be generalized and those that may only apply to specific situations.

RISKS OF UTERINE RUPTURE IN FUTURE PREGNANCIES FOLLOWING INITIAL CESAREAN BIRTH

A recent study published in *The New England Journal of Medicine* has captured the public's attention. This study demonstrated that cesarean delivery can increase the risk of uterine rupture during labor in a subsequent pregnancy. Researchers analyzed records of over 20,000 women who gave birth to a second child after an earlier cesarean delivery. The risk of uterine rupture when having a second cesarean delivery with no labor is 1.6 per 1,000 births. The risk of rupture during spontaneous labor for this population is over three times as great, and if prostaglandins are used to induce labor, the risk increases 15 fold. Since 60 percent of women with prior cesarean deliveries attempt labor with the next pregnancy, this is important information for use in patient education. Mothers-to-be also need to know that initial cesarean delivery will affect future births.

LEARNING DEFICITS IN CHILDREN TREATED FOR ACUTE LYMPHOBLASTIC LEUKEMIA

For children with Acute Lymphoblastic Leukemia, who now have considerably improved long-term, disease-free survival rates, there are also long-term consequences, including academic difficulties caused by aggressive, life-saving treatments. These treatments involve the central nervous system and include whole brain radiation and high dose chemotherapy. Nursing research has shown that these children have declines

in arithmetic, verbal fluency and visual and motor-related skills, which affect their success in school. Young survivors showed these deficits for up to four years after their treatment regimens ended. A pilot study testing a remedial math intervention to minimize this type of deficit has shown early positive results. A larger study to test this intervention is now in progress.

REDUCING RISKS OF A SECOND CARDIAC ARREST

In addition to finding ways to reduce or eliminate treatment side effects, nursing research also examines how to lower risks accompanying disease. Preliminary results of a biobehavioral intervention on patients who had cardiac arrest showed that there was an 86 percent reduction of mortality from cardiovascular disease in these patients for up to two years. The intervention consisted of training in physiological relaxation using biofeedback; coping skills for depression, anxiety, and anger; and health education about cardiovascular risks. Although the underlying reasons for these positive results are not fully understood, it is hypothesized that decreases in psychological distress improve cardiovascular prognosis. This study underscores the importance of biobehavioral approaches for survivors of cardiac arrest.

NEW AND EXPANDED INITIATIVES

In FY 2003, NINR plans to expand activities that address the health disparities prevalent in our society by incorporating such factors as ethnicity, culture, gender, socioeconomic status, and geography. This area has always been an important tenet of nursing science and is one of its special strengths. Since ethnic minority groups have a number of health problems associated with higher morbidity and mortality rates than do majority groups, NINR will continue to focus on these issues. A major new emphasis will be on community research partnerships in which community members help to identify and address key health concerns. A workshop to delineate possible

research areas and strategies was held earlier this year to begin this activity.

As the Committee is aware, NINR is advancing research on end-of-life and palliative care, and is the lead coordinator of NIH research in this area. In addition to investigating new models for palliative care, next year we plan to focus on pediatric and genetic end-of-life issues, with continued efforts to include minorities in our research programs.

Next year NINR will expand the research agenda to address care issues for residents in long-term facilities, such as nursing homes and assisted living. The number of assisted living residents is projected to increase from approximately 1 million in 1998 to more than 1.7 million in 2025, according to the National Center for Assisted Living. NINR plans to solicit studies that deal with issues such as residents' functional mobility, transitional problems in adjusting to their loss of independent living, and prevention of falls and depression,

Another emphasis is health promotion for adolescents to reduce their high-risk behaviors that will affect their health later in life. We will encourage studies that test health promotion interventions to decrease smoking, substance abuse, and risky sexual behavior, and improve nutritional status in school, at work, and in community-based settings. Research to test culturally and linguistically appropriate interventions involving ethnic minorities will provide valuable answers to address these problems.

Since nursing research is important to improve better health, it is imperative that NINR work at building future capacity. The nursing shortage will impact nursing research by reducing the number of investigators available to conduct studies that add to the scientific base for practice. To ensure a stable research workforce for the future, NINR plans to use several new approaches, including earlier entry to research careers. Research career development of minority nurses will be emphasized to enhance

research on health disparities. One innovative strategy is being carried out in collaboration with the new National Center on Minority Health and Health Disparities. Together we developed pilot research partnerships between established research intensive institutions and minority-serving institutions. The goal was to increase diversity in the nurse researcher pool and to increase research to reduce health disparities. The second phase of this activity is currently under way and shows much promise.

The NIH budget request includes the performance information required by the Government Performance and Results Act (GPRA) of 1993. Prominent in the performance data is NIH's second annual performance report which compared our FY 2001 results to the goals in our FY 2001 performance plan.

In closing, we are in a high pressure period of increasing demands for empirically based nursing care, while facing a possible diminution of both nurses and nurse researchers. Research provides career challenges for nurses that will stimulate their intelligence, their empathy, and their energy. Nursing research offers the opportunity to enhance the health for all of our Nation's people.

Thank you, Mr. Chairman. I will be pleased to answer questions the Committee may have.

