

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Statement by

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on

Fiscal Year 2001 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 non-AIDS budget request for the National Institute of Nursing Research (NINR) for FY 2001, a sum of \$84,714,000, which reflects an increase of \$2,672,000 over the comparable Fiscal Year 2000 appropriation. Including the estimated allocation for AIDS, total support requested for NINR is \$92,524,000, an increase of \$ 2,985,000 over the Fiscal Year 2000 appropriation. Funds for the NINR efforts in AIDS research are included within the Office of AIDS Research budget request.

I would like to thank the Committee for your interest and support for NINR and for nursing research. In this period of rapid technological and demographic change, it is imperative that nursing research grow to help meet present and future needs and expectations of our nation's people for improved health care. More people will live longer and face chronic illness and disabilities in older age. More will be caregivers who will need to know how to live their own lives while caring for ill relatives and friends. Many will be minorities at risk for experiencing disparities in the incidence, prevalence and seriousness of disease and access to care. How people live and how they experience illness will be influenced by new technologies in the healthcare system. Increasingly, they will demand a role in managing their own health. Individuals will appreciate the value of prevention, but will still need help in achieving healthier lifestyles. And virtually everyone wants to die with dignity and a sense of control. Today I will discuss our targets for FY 2001 that relate to these concerns.

CHRONIC DISEASE -- A LONG-RANGE VIEW ABOUT LONG-TERM ILLNESS

Chronic illness continues to be an important NINR research emphasis. We are investigating how to both avoid complications of disease and disability and control symptoms such as pain, nausea and poor sleep. Other studies will be directed at patients who are discharged early from the hospital and still need substantial care at home. A special focus will be on family caregivers, who have varying expertise and financial and complex care demands for multiple lengthy illnesses.

In addressing early hospital discharge, recent nursing research has verified the value of a transitional care model that has been tested in several patient populations. The model uses a multidisciplinary team and involves comprehensive discharge planning, including determination of patient care needs outside the hospital, and follow-up in the home by advanced practice nurses specializing in geriatrics. As the chart shows, six months following discharge, the intervention group of older adults with

common medical and surgical problems had 48 percent fewer rehospitalizations, 54 percent fewer multiple hospital readmissions, and 65 percent fewer days in the hospital at a 48 percent savings to the healthcare system when compared to controls. Widespread use of this model could save significant healthcare dollars and improve quality of care.

Early hospital discharge has placed a research spotlight on family caregivers, who often undertake the responsibility for care of their ill relatives. Caregivers of Alzheimer's patients bear special burdens. They must cope with the physical downward spiral of illness, and they also must deal with the stress of patients' behavioral problems that include agitation, depression, and wandering. Nurse researchers have developed a successful intervention that offers behavioral management skill training to caregivers. Five months after the intervention, researchers found that caregiver stress continued to be reduced when coping with disruptive behaviors of older adults in their care. The study also showed a moderate decrease in caregivers' perceptions of their burdens in providing care. Furthermore, those who were initially depressed were less depressed. These positive results may be applicable to caregivers of patients with other chronic illnesses, such as stroke or congestive heart failure.

A life-long chronic illness that often starts in childhood, Type I diabetes, represents 5 to 10 percent of the total number of people with diabetes, and can seriously impact physical health and quality of life. Our research on adolescents with this condition compared two types of recommended intensive therapies -- either multiple daily injections of insulin -- three or more a day -- or subcutaneous infusion of insulin delivered by insulin pump -- a therapy which is currently used by fewer than 5 percent of young people. Adjusting to the insulin pump has been difficult for young adults, but when they are provided with an intervention consisting of instruction and support, the outcomes have been positive. Advanced practice nurses visited the adolescents every four to six weeks and provided them with diabetes education, adjustments in managing their diabetes and clinical assessments, including measurements of hypoglycemia and adherence to dietary restrictions. Investigators found that compared to teens on multiple daily injections of insulin, those who used the insulin pump had fewer severe hypoglycemic episodes and were able to maintain their blood glucose levels within the proper range. The "pump" group scores also showed better self esteem, coping skills, and quality of life. This finding identifies the education and support that enables adolescents to use the newer pump technology effectively.

NINR is committed to expand chronic illness research in FY 2001 to help patients manage their conditions over time. This involves a major investment of resources. We will focus on strategies to be applied broadly across chronic illnesses, including prevention of disease and its complications, self-monitoring by patients of the course of their disease, and promotion of patient success in problem solving and in maintaining a healthy lifestyle.

THE END OF LIFE -- AN EMERGING RESEARCH FOCUS

Just as biomedical advances are changing the way we live with illness, they are also changing the way we eventually die. The duration of both chronic illness and the dying process has been prolonged. In FY 2001, we will expand our focus on end of life to better understand at what point palliative care becomes the primary goal. We also need to know how best to facilitate communication and decision making among all involved in the end-of-life period -- the patient, nurse, physician, family, and friends.

NINR is pleased that the response to last year's Request for Applications for research on end-of-life

care resulted in more than 100 applications -- an impressive result for a relatively new area of research. Those that were funded will form a basis upon which to build an important, growing effort.

HEALTH DISPARITIES -- CLOSING THE GAP

Another area of importance to nursing research and to the nation is reduction of persistent health disparities among certain populations in our country. We must provide interventions that are more responsive to the needs of our multiethnic and multicultural society. Nursing research has long incorporated ethnic and cultural factors in designing projects and testing interventions -- with the goal of tailoring care to the individual patient's needs. Yet more research is needed to identify why disparities exist and what to do about them.

Let me provide an example of nursing research that addresses an area of disparity in a growing population. For many years, there were few resources available for Hispanics with arthritis to help them manage their condition. Limited fluency in English had the effect of excluding them from most health research projects. In response to this need, nurse researchers developed and tested a successful Spanish language arthritis education program. This endeavor was not limited to translation from English to Spanish. Cultural differences within Latino communities and accurate Spanish language measurement tools were also addressed. During the program, patients learned how to exercise, communicate with health care professionals, and manage pain, fatigue and depression. Throughout a one-year period, patients experienced significant improvements in all areas. The components of this course have provided a useful model that is being tested for Hispanic populations with coronary artery disease, chronic obstructive pulmonary disease, and Type II diabetes.

NINR plans to continue its ongoing programs next year to help eradicate healthcare disparities. We will focus specifically on diabetes and its gaps in morbidity across ethnic groups. We will emphasize strategies for effective self-management of illness, and investigate the influence on health of genetics, education, poverty, diet, behavior and social support. Another goal is to increase the number of well-trained investigators to conduct minority health research. To do this, we plan to expand core research centers and career development opportunities.

CLINICAL RESEARCH

Most nursing research studies are clinical in nature, although they can also involve basic research. An example of a recent finding concerns the use of feeding tubes to provide required nutrition. Every year an estimated one million hospital patients or residents of nursing homes are fed through use of feeding tubes. Incorrect insertion or dislocation of the tube may deliver food to the respiratory system, which can be fatal to the patient. Studies have shown that current clinical methods that rely on a stethoscope rather than X-rays for tube placement are correct only 6 to 34 percent of the time. Nurse investigators have discovered that an accurate, less costly alternative to both techniques is measuring pH and bilirubin levels in aspirated contents from the feeding tube. This method has identified the misplacement of tubes in lungs with 100 percent accuracy and is less expensive and safer than repeated X-rays.

Another important innovation for clinical research and practice is telehealth -- a long distance technology to reach underserved areas, such as rural communities. NINR has been active in supporting telehealth studies for treatment and monitoring of patients and for providing health

information. In the next fiscal year, NINR plans to expand research to determine the effects of telehealth on various patient populations and cost savings associated with telehealth strategies. We also plan to target patients most likely to benefit from telehealth interventions, identify barriers, and find ways to integrate telehealth into other treatment and care regimens.

BUILDING NURSING RESEARCH CAPACITY

Next year provides an opportunity to initiate new programs to increase the nursing research capacity. In the current fiscal year, we are launching the Summer Genetics Institute for extramural researchers. This new eight-week training course emphasizes genetics in clinical practice, in the research laboratory, and in nursing curricula. Other training initiatives include an intramural career transition award that combines postdoctoral training with subsequent support for beginning research at an extramural institution.

NINR continues its collaboration with the Office of Research on Minority Health in a career development program for minority nurse researchers. Studies being carried out by these minority investigators include reduction of serious developmental problems of migrant infants, suicide prevention in a population of rural Indian youth, and improving screening for prostate cancer in African-American men. NINR is also collaborating with the National Coalition of Ethnic Nursing Associations on a workshop to identify important research questions and training needs for minority nurse scientists.

GOVERNMENT PERFORMANCE AND RESULTS ACT (GPRA)

Prominent in the GPRA performance data is NIH's first performance report which compares our FY 1999 results to the goals in our FY 1999 performance plan. As our performance measures mature and performance trends emerge, the GPRA data will serve as indicators to support the identification of strategies and objectives to continuously improve programs across the NIH and the Department

CONCLUSION

In conclusion, health research, health care, and health choices are increasingly interdependent, and nurses and nurse researchers play a vital role in all three areas. Continued growth of nursing research is critical to meet public demands and urgent national health needs. Our contributions to the scientific foundation that nourishes the work of healthcare practitioners are already making a difference in health care or have significant potential to do so. This base of knowledge merits expansion in creative new directions. NINR looks forward to the challenge.

Mr. Chairman, I am pleased to answer any questions the Committee may have.

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