

# New UIC center to study end-of-life transition

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The University of Illinois at Chicago College of Nursing has received a federal grant to create a center to study people as they transition to the end of life.

The UIC Center for End-of-Life Transition Research will advance the science of care for people of all ages facing death -- infants, children, adults and older adults. It is funded through a \$2.4 million grant from the National Institute of Nursing Research, one of the National Institutes of Health.

"The American health care system often fails in providing appropriate care to people facing the end-of-life transition," said center director Diana Wilkie, professor and Harriet Werley Endowed Chair for Nursing Research. "More than half of the people dying of cancer do so with their pain unrelieved and their expressed wishes about life-sustaining treatments not honored."

Research also suggests that parents of children who died felt that their children suffered greatly during the last month of life, said Karen Kavanaugh, professor of maternal-child nursing and co-director of the center.

The new center, Kavanaugh said, will conduct research to foster "patient-centered, family-focused, respectful death" and planning for end-of-life care that is consistent with the patients' and families' values and priorities.

"The new center is a landmark opportunity to make important advances for palliative and end-of-life care," Kavanaugh said.

Four studies led by an interdisciplinary team from various colleges throughout UIC will be conducted during the five-year project.

One project will predict end-of-life in patients with advanced heart failure. Despite recent advances in drug and device therapy, the long-term prognosis of patients with advanced heart failure remains poor, says Catherine Ryan, research assistant professor of nursing and an expert in critical care, who will conduct the study.

"More than 5 million people live with advanced heart failure, and accurately predicting the end of the illness trajectory for people with this disease will be extremely beneficial to direct care," Ryan said. Such knowledge, she said, could reduce the annual cost of care for these patients -- a cost estimated for 2007 to be \$33.2 billion.

Another study will focus on oral health problems in terminally ill cancer patients in hospice care. Dr. Dena Fischer, assistant professor of oral medicine and diagnostic sciences in the UIC College of Dentistry, will direct the study.

"Oral health problems are common for patients in the end of life, though such problems have gone largely unrecognized and may contribute to symptom burden during end-of-life transition," Fischer said. "Our study will be taken from the perspectives of the patient, primary caregiver and oral health professional to determine the primary caregiver's knowledge about oral health problems and treatment."

A third study will utilize a suicide prevention online video to learn how it can raise suicide awareness among Asian American and Caucasian college students in Chicago. Students will complete computerized

questionnaires about their cultural orientation and attitudes about suicide after watching the video. The study will be directed by Aruna Jha, research assistant professor of nursing, who has a background in social work.

Jha said Asian Americans have recently emerged as the group with the fastest increase in rates of suicide deaths for men and women aged 20 to 24. "Their rates are now equal to other races in suicide attempts among high school students, and one and a half times the likelihood of whites for serious suicidal intent among college students. This gap is particularly disturbing given the availability of a well-accepted suicide awareness videotape."

Teresa Savage, research assistant professor of nursing, will conduct a fourth project, which will address end-of-life issues for patients with intellectual or developmental disabilities.

"There are more than 4 million people in the United States who have an intellectual or developmental disability," Savage said. "They are a disenfranchised group in the health care system, and many of these individuals are left out of decision-making regarding their own health care, especially at the end of their life."

Savage and her research team will conduct focus groups with developmentally disabled patients, support staff caregivers and family caregivers to learn about their perceptions of end-of-life care.

Other College of Nursing faculty with leadership roles in the new center are Sandy Burgener, associate professor of medical-surgical nursing; Laura Szalacha, research assistant professor of public health, mental health, and administrative nursing; Marquis Foreman, professor of medical-surgical nursing; and Gail Keenan, associate professor of public health, mental health and administrative nursing. An interdisciplinary

group of UIC faculty from the health sciences and computer sciences will also participate in the new center.

Source: University of Illinois at Chicago

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