Medical Xpress

Columbia Nursing develops online tool to reduce stress in Hispanic caregivers of dementia patients

June 11 2013

Dementia often claims two victims: The patient and the caregiver. That's because caring for people with dementia requires close supervision and constant care, which can place a caregiver's psychological, physical and financial health at risk.

Dementia prevalence is more than twice as high nationally in Hispanics than in non-Hispanic whites. Most research to identify the stress factors of dementia caregivers has predominately focused on the general population, not on the Hispanic community where caregiver burden for dementia patients is significantly higher.

Now, a team of researchers, led by Robert J. Lucero, Ph.D., MPH, RN, Assistant Professor at the Columbia University School of Nursing, will develop and test a web-based intervention to facilitate the health and health care management for patients with dementia and their caregivers. The goal of the Family-Health Information Management System (Family-HIMS) is help improve the caregiver's ability to manage the complex web of health and health care information associated with the health care needs of a patient with dementia.

The Family-HIMS is intended to enhance the users' ability to access, visualize, organize, and coordinate health information and health care needs of dementia patients and their caregivers. Lucero and his team will build on previous experience of successfully designing and developing

consumer-based [health information technology](link). English- and Spanish-speaking [family caregivers](link) will engage in the design, development, and testing of the Family-HIMS to help researchers incorporate differences among the information seeking and management behaviors of Hispanic caregivers.

"The aim of this health information management system is to develop a web-based tool that conforms to the needs of the Hispanic caregiving community and to evaluate its impact on helping caregivers manage their health and the health of the person they are caring for," says Lucero, who is basing his approach on a similar web-based tool he developed to improve the self-assessment and management for falls in community dwelling older adults.

Hispanics face unique caregiving experiences and stressors. For example, studies show that when caregiver stress leads to nursing home placement for a person with dementia, feelings of guilt are more common in Hispanics, who are less likely to delegate the care of affected relatives to outside agencies. When compared to their non-Hispanic White and non-Hispanic Black counterparts, Hispanic caregivers are more depressed, usually younger, and more likely to have children or grandchildren under the age of 18 in their household.

Technology-based family caregiver interventions can lessen caregiver stress, reduce isolation, fill gaps in information, and assist caregivers to manage health care services, as well as reinforce healthy behaviors for themselves and a family member with dementia. However, it is not known if these types of interventions are effective in Hispanics. The design and development of the Family-HIMS will incorporate the expressed needs of Hispanic caregivers of dementia patients, and will be the first web-based [health information](link) management system tested among English- and Spanish- speaking Hispanic caregivers.

Family-HIMS Part of a Broad Research Program Seeking to Better Understand the Social and Demographic Factors associated with Hispanic Caregivers of Dementia Patients

The Family-HIMS project is one of three components in a larger research effort funded by the National Institutes of Health/National Institute of Nursing Research. The New-York-City Hispanic-dementia-caregiver Research Program (NHiRP) is a multifaceted, multi-institutional initiative, combining the expertise of its principal investigators in the areas of minority health, epidemiology, clinical trials, mental health, and bioinformatics. Along with Lucero, the program is co-led by Jose Luchsinger, MD, MPH, Associate Professor of Medicine and Epidemiology at Columbia University Medical Center; and Mary Mittelman, DrPH, Professor of Psychiatry at New York University (NYU) Langone Medical Center.

The two additional NHiRP components are to: 1) conduct a 5-year longitudinal study of mid and long-term outcomes of Hispanic caregivers who participated in a randomized trial of the NYU Caregiver Intervention; and 2) create a registry of Hispanic caregivers to study socio-demographic factors in the context of caregiving-related needs.

As part of the longitudinal study, the study team will observe at 1 and 5 years whether caregivers who received the NYU Caregiver Intervention report significantly fewer depressive symptoms and less burden than caregivers who did not receive the intervention. The caregiver registry will be comprised of 300 individuals who are primarily responsible for the health care needs of a patient with dementia. A large-scale interviewed-based survey will be conducted to examine the interplay of key socio-demographic characteristics, caregiver burden, stress, and depressive symptoms. These factors will be measured against such

characteristics including sex, family position, employment, acculturation, and socioeconomic status.

"Information on caregiver interventions for [Hispanics](#) is limited," says Lucero. "This research program is one of the largest studies of its kind to study the long-term effectiveness of culturally-sensitive counseling and support groups, and test a novel technology-based intervention that supports education and health management for Hispanic caregivers."

Provided by Columbia University Medical Center