

Contact: Anne DeLotto Baier

abaier@hsc.usf.edu

813-974-3300

[University of South Florida Health](#)

Improving coping skills benefits family caregivers of hospice patients with cancer

Caregivers of cancer patients dying at home significantly benefited from supportive educational sessions in which hospice nurses taught the caregivers how to cope with distressing patient symptoms, researchers at the University of South Florida report.

The study – one of the first randomized clinical trials conducted with caregivers of patients near the end of life – was funded by the National Cancer Institute and National Institute for Nursing Research. It was published online Dec. 2 in *Cancer*, the journal of the American Cancer Society, and will appear in January's printed issue.

As many as 52 million Americans assist family members with an illness or disability, including many who provide extensive care for relatives with cancer. Previous studies have shown highly stressed family caregivers are at higher risk for depression, health problems and increased death rates.

"There has been little prior data to describe which caregivers are at greatest risk for distress and which interventions are likely to relieve that distress," said USF nursing professor Susan McMillan, PhD, RN, lead author for the study. "We found that caregivers benefited from even a small number of sessions with the interventionists, above and beyond the benefits gained from hospice care alone."

The Tampa study looked at the effects of a structured psychoeducational intervention for family members caring for terminally ill cancer patients at home. Dr. McMillan, a member of the USF Center for Hospice, Palliative Care and End of Life Studies, worked with a team of researchers at the USF College of Nursing, the USF School of Aging Studies, the USF Division of Geriatric Medicine, the H. Lee Moffitt Cancer Center & Research Institute, and LifePath Hospice and Palliative Care.

In addition to providing standard hospice care, nurses participating in the study taught family caregivers how to better assess and cope with specific cancer symptoms such as pain, constipation and difficulty breathing. The researchers compared this group to caregivers of patients receiving hospice care alone and caregivers of patients receiving hospice care and supportive visits. Dr. McMillan found that with interventions, caregiver quality of life increased while the burden from caregiving, and caregiver distress were significantly reduced.

Family caregivers are central to end-of-life care because they offer emotional support, help with activities of daily living and medications, and communicate with health care professionals about the patient's condition. Yet, caregivers -- many of whom are elderly spouses with their own health problems -- may experience significant strain and anxiety -- from taking care of seriously ill patients, Dr. McMillan said.

"In today's health care system, patients simply don't have the option of being hospitalized for long periods, including at the end of life," she said. "And, most patients tell you they want to be able to die comfortably at home in their own beds. But, that can only happen if we adequately prepare family members to provide extensive care for their loved ones at home."

End-of-life care studies, primarily focused on cancer patients and their caregivers, should be expanded to include other hospice populations, including those with end-stage heart disease, chronic obstructive pulmonary disease and dementia, the researchers recommend.

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Other study researchers were Brent Small, PhD; Michael Weitzner, MD; Ronald Schonwetter, MD; Mary Tittle, PhD; Linda Moody, PhD; and William Haley, PhD.