

Early, phone-based, palliative care support improves caregiver quality of life and patient survival

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The earlier a specific phone-based, palliative care support program can be introduced to caregivers, the better they will be able to cope with the caregiving experience, according to research conducted by University of

Alabama at Birmingham School of Nursing investigators.

The patient outcomes from the study, known as ENABLE III, were presented June 3 at the American Society of Clinical Oncology Annual Meeting in Chicago by Marie Bakitas, D.N.Sc., associate director in the Center for Palliative and Supportive Care in the Department of Medicine. J. Nicholas Dionne-Odom, Ph.D., R.N., a postdoctoral fellow in the UAB Cancer Prevention and Control Training Program and researcher in the School of Nursing, will present the caregiver outcomes from the study.

"Family [caregivers](#) are a crucial part of the patient-care team. Because the well-being of one affects the well-being of the other in a reciprocal way, both parties benefit when caregivers receive [palliative care](#)," said Bakitas, the senior study author and Marie L. O'Koren Endowed Chair. "We found that, when caregivers began receiving palliative care support around the time of the patient's advanced cancer diagnosis, they had less depression, perceived themselves to be less burdened by performing caregiving tasks and had better quality of life."

In this National Institute of Nursing Research-funded study—one of the first to use a patient and caregiver palliative care intervention in parallel—207 [patients](#) with recurrent or metastatic cancer and 122 [family caregivers](#) received palliative care support via a phone-based intervention. One group of patients and family caregivers started receiving this intervention within two weeks of randomization (immediate group), and another group started 12 weeks later (delayed group).

After enrollment and an in-person palliative care assessment, advanced practice palliative care nurses delivered a phone-based curriculum (Charting Your Course) and provided monthly supportive care follow-up to patients and caregivers by telephone. The curriculum covers how to

manage problems using creativity, optimism, planning and expert information; self-care including healthy eating, exercise and relaxation; how to effectively partner with care recipients in managing symptoms; how to build a support network; and decision-making, decision support and advance care planning. The Charting Your Course curriculum was developed for the purposes of this research study, and it is publicly available. Telephone delivery of the program simplified access to the support for caregivers in rural areas.

Researchers found the patients had a longer survival and the caregivers' overall quality of life, depression and burden were all improved in the immediate group versus the delayed group. "Unfortunately, the full range of [palliative care services](#) is rarely taken advantage of because palliative care is often introduced too late in the course of cancer treatment," Bakitas said. "Patients and caregivers should understand that palliative care is not end-of-life care but rather an extra layer of support that can be offered along with curative medical treatments."

Palliative care is focused on providing patients with relief from the symptoms, pain and stress of a serious illness. By definition, it is a partnership of patient, medical specialists and family with the goal of improving quality of life for both the patient and the family.

Dionne-Odom, the lead author on the caregiver study, noted there are few organized palliative care programs for caregivers of patients with advanced cancer, and reimbursement for this type of counseling is very limited. An online family care navigator tool from the Family Caregiver Alliance's National Center on Caregiving website may help family caregivers find assistance in their local area.

Provided by University of Alabama at Birmingham

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