

Support team aiding caregivers of cancer patients shows success, researchers report

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Many caregivers of terminal cancer patients suffer depression and report regret and guilt from feeling they could have done more to eliminate side effects and relieve the pain.

So researchers from the nursing school at Case Western Reserve University devised and tested an intervention that quickly integrates a cancer support team to guide <u>caregivers</u> and their <u>patients</u> through difficult end-of-life treatment and decisions.

In the study, caregivers reported a high degree of satisfaction from having a team comprised of an advance practice nurse, social worker, a spiritual advisor and the patient's oncologist explain what was happening and why during the dying process.

The positive outcomes of having a support team inform and allow caregivers and their patients an opportunity to think through what was important and what actions to take as the disease progressed are reported in the July issue of *Oncology Nursing Forum*. The National Institute of Nursing Research and the National Cancer Institute (grant: NR018717) funded the study.

The intervention's support team got involved in end-of-life conversations with the patient and caregiver at the first diagnosis of a late-stage cancer.

In the past, many of those conversations started too late—days or weeks



before the patient died, said Sara Douglas, PhD, RN, associate professor at Case Western Reserve's Frances Payne Bolton School of Nursing and lead author.

"We owe it to the patients and caregivers to start earlier and think the choices through," said Douglas, who conducted the research with CWRU colleague and principal investigator, Barbara Daly, PhD, RN, FAAN, professor of nursing.

The methodology

- Their intervention concept follows a larger study of 610 advanced cancer patients and their caregivers at Case Medical Center-Seidman Cancer Center in Cleveland, Ohio, between 2008 and 2012.
- From that study, the researchers analyzed data from 106 caregivers with loved ones who died from lung, gastrointestinal or gynecological cancers. They were divided into two groups: one who had received the cancer support team and one without the additional support.
- For those who received the cancer support team, a member of the team checked in with the caregiver monthly to answer questions and discuss the patient's care and progress. At any time the caregiver had concerns, the team was available.
- Studied over 15 months, participants were asked about their mood and social supports when recruited, and again at three, nine and 15 months to gauge whether the intervention made a difference in their moods, social support and satisfaction with end-of-life care. They were also questioned after their loved one died about the patient's care in the last week of life.
- Neither group showed changes in mood and feelings of social support. But caregivers with the aid of the cancer support team showed a higher satisfaction with end-of-life care in five areas:



pain relief, managing pain, speed in treating symptoms, information about side effects and coordination of care.

The measureable benefit to grieving families of having had access to comprehensive support prior to the death of their loved one reinforces the need to include families in cancer care, Douglas said. The researchers contend support services targeting psychosocial needs of patients and families should be incorporated as routine adjuncts to cancer-directed therapy, and that this type of team-oriented approach is an effective means to do so.

"The perception that the caregiver's loved one was well cared for can have long-term benefits in easing possible regrets that may occur after someone has died," Douglas said.

These findings will be shared with the oncology clinical community.

Provided by Case Western Reserve University

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