

Distance caregivers for advanced cancer patients have special needs

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By 2012, an estimated 14 million people will serve as distance caregivers to family members who live across the state, across the region, even across the country.

"No longer are families living just around the corner from each other," says Polly Mazanec, an assistant professor at the Frances Payne Bolton School of Nursing and an advance practice oncology [nurse](#) at University Hospitals Case Medical Center's Seidman [Cancer Center](#).

The distance presents a challenge as family members work to gain information about their loved ones and participate in their [cancer care](#). But it's also challenging to the local [caregivers](#)-nurses, doctors and local family members-who must adapt short-term to these remote caregivers' special needs. In hospitals across the country, such challenges have prompted distance caregivers to be labeled "seagulls" and "pigeons"-references to family members who fly in, make a mess and fly out.

Distance caregivers are gaining in numbers, according to Mazanec, who is lead investigator on the study, "Distance Caregiving a Parent with Advanced Cancer." In the [Oncology Nursing Forum](#) article, "Lack of Communication and Control: Experience of Distance Caregivers of Patients," she reports on the qualitative findings from the study.

Mazanec says what she and her fellow researchers found requires a change in the way information is delivered to distance caregivers.

Nurses, she says, can have a role in easing some of the emotional stress experienced by distant family members.

The majority of the distance caregivers are secondary caregivers with local family members relaying patient information secondhand and often by phone, Mazanec says.

With sparse how-to information available to help these individuals, Mazanec first wanted to understand what bothered these caregivers and then develop an intervention to bring them into the loop of patient care.

The study, part of a larger look at distance caregiving, involved telephone interviews with caregivers for patients with advanced lung, gastrointestinal and gynecologic malignancies. Each interviewee lived 100 miles or more away from their family member and answered three open-ended questions that were taped and later transcribed.

Common themes were a lack of control and information, but what emerged beyond those key concerns were the following:

- Distance caregivers struggle emotionally about the right time to visit or call their family members. Many caregivers have families with young children and possibly limited financial means to travel.
- Uncertainty about what was happening with their [family members](#) also concerned the caregivers.
- Even though the caregivers were highly educated and many sought information online, they still wanted more information from the health care professionals.
- Even though parents of these caregivers were ill, they still wanted to protect their children by withholding information that sons and daughters wanted to know. Likewise the children withheld information to protect or lessen the stress of their ill parent.

- Caregivers felt it was important to stay connected.

Mazanec says that with new technologies available, she hopes to design a program that closes the distance gap.

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