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Cancer caregivers experience unique burdens compared with other conditions

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An analysis of data from more than 1,200 caregivers in the United States finds that cancer caregivers report a higher burden and spend significantly more hours per week caregiving, as opposed to individuals who care for people with other conditions. The analysis was based on survey data from the National Alliance for Caregiving, which estimates that there are 2.8 million caregivers providing care for an adult family member or friend with cancer.

The findings shed light on the state of cancer caregiving in the United States. This study will be presented at the upcoming 2016 Palliative Care in Oncology Symposium in San Francisco.

"Our research demonstrates the ripple effect that cancer has on families and patient support systems," said study researcher Erin Kent, PhD, MS, program director in the Outcomes Research Branch of the Healthcare Delivery Research Program of the National Cancer Institute (NCI). "Caregiving can be extremely stressful and demanding - physically, emotionally, and financially. The data show we need to do a better job of supporting these individuals as their wellbeing is essential to the patient's quality of life and outcomes."

Dr. Kent emphasized the cyclical nature of cancer care, often requiring short, yet highly intense periods of time where patients undergo active treatment, such as chemotherapy, as a possible reason for the increased intensity in caregiving. She noted such intensity is also associated with increased caregiver stress and depression.

The data, extracted from the 2015 Caregiving in the U.S. study, showed cancer caregivers were 63% more likely to experience a higher burden than non-cancer caregivers. Cancer caregivers also reported spending nearly 50% more hours per week providing care than non-cancer caregivers.

Researchers also found that cancer caregivers were more likely to communicate with health care professionals, and to advocate on behalf of the patient (62% of cancer caregivers vs. 49% of non-cancer caregivers). Despite high levels of engagement with providers, cancer caregivers were twice as likely to report needing more help and information with making end-of-life decisions.

Dr. Kent stated that data on caregiving is difficult to collect and stressed the importance of these population-level findings. In addition, she underscored the need for additional research on cancer caregivers.

"Based on our findings, it's clear we need additional research on caregiving to better understand at what point providers and clinicians should intervene to assess the wellbeing of caregivers. Technology, combined with use of a clinical distress rating system, could be promising in the future as a means to ensure caregivers are being supported in a meaningful way," Dr. Kent said.

Provided by American Society of Clinical Oncology

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