

Study finds most caregivers of cancer patients are not screened for distress

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Being diagnosed with a serious illness such as cancer brings many physical, emotional and financial burdens, not only for patients, but for their caregivers as well. However, a new study from researchers at Wake

Forest University School of Medicine shows that caregivers of adult cancer patients are often overlooked in cancer care.

The study was published in the [Journal of the National Cancer Institute](#).

"The role of the [caregiver](#) is incredibly important, but it's also very challenging," said Chandysten Nightingale, Ph.D., assistant professor of social sciences and [health policy](#) at Wake Forest University School of Medicine and co-principal investigator of the study. "Caregiver well-being is crucial because there is evidence to suggest that happy and healthy caregivers provide better support and care to their loved ones, potentially leading to better patient outcomes and even reduced burden for our health care systems."

For the observational study, the research team collected data in collaboration with the National Cancer Institute Community Oncology Research Program (NCORP).

Supportive care leaders at the NCORP sites completed online survey questions related to caregivers, distress screening and distress management strategies at their oncology practices.

"We found that 92.5% of practices screen patients for distress. However, only 16% routinely screen caregivers," Nightingale said.

The research team also looked at the number of sites that not only identified caregivers but also screened them and had referral strategies in place for those who screened positive.

"When we looked at the sites that were comprehensively doing all of that, it was less than 13%," Nightingale said. "When we analyzed the same for patients—screening and referral resources—we found that 90.6% of the sites were doing that."

According to Nightingale, distress screening for caregivers doesn't have to be a complex process. Oncology practices could implement a single-item distress thermometer, which is one question on a scale of 0 to 10.

"We do need to better understand the unique barriers in community oncology settings that are preventing systematic screening for caregivers," Nightingale said. "Our findings suggest that patient distress screening is widespread among community oncology clinics. However, very few are comprehensively engaging caregivers."

"Defeating cancer is a team effort, and I commend Dr. Nightingale and the entire team for looking at such an important issue," said Ruben Mesa, M.D., president of Atrium Health Levine Cancer, executive director of Wake Forest Baptist's Comprehensive Cancer Center and vice dean for cancer programs at Wake Forest University School of Medicine.

"The hope is that we can leverage existing processes for patients and translate them to caregivers to make sure we are providing the best possible support for patients across the country who are facing [cancer](#)."

Going forward, the research team aims to have a better understanding of the barriers that prevent caregiver screening and how to make supportive care services more accessible.

More information: Chandylen Nightingale, Processes for Identifying Caregivers and Screening for Caregiver and Patient Distress in Community Oncology: Results from WF-1803CD, *Journal of the National Cancer Institute* (2023). [DOI: 10.1093/jnci/djad198](https://doi.org/10.1093/jnci/djad198)

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