

Study shows symptoms linked to poor quality of life in long-term childhood cancer survivors

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Due to improved treatments and technologies, more children than ever are surviving cancer. Unfortunately, about 70 percent of these children experience late effects from their disease and treatment 30 years after their cancer diagnosis, which University of Florida Health researchers say significantly impact their quality of life.

"The prevalence of these symptoms accounts for a huge variance in physical, mental and social domains of quality of life among survivors," said I-Chan Huang, Ph.D., an associate professor of health outcomes and policy in the UF College of Medicine and the lead author of the study. "If we think symptoms are the key to patients' quality of life, then if we can better manage their symptoms, we can improve their daily functional status and quality of life."

Huang, also a member of UF's Institute for Child Health Policy, teamed with researchers from St. Jude Children's Research Hospital in Memphis to conduct the study, which was published in the Nov. 20 issue of the *Journal of Clinical Oncology*.

The researchers analyzed data from 1,667 [childhood cancer survivors](#) who participated in a St. Jude study looking at the long-term effects of cancer survival. The researchers used a patient-reported survey to measure quality of life. A specific symptom scale was designed to assess toxicities related to cancer treatment, as outlined in the Children's

Oncology Group guidelines.

The most common symptoms patients reported were head pain, pain in the back and neck, pain in areas other than the back and neck, disfigurement such as hair loss and sensation abnormalities.

According to the research findings, participants' ratings of their own physical and mental quality of life dipped lower and lower for each additional symptom they reported. Participants also reported more symptoms over time, with survivors reporting late effects up to 40 years after they were initially diagnosed with cancer. According to a report from the Institute of Medicine, approximately one in every 600 adults between the ages of 20 to 39 is a survivor of childhood cancer.

About 70 percent of participants reported experiencing at least one late effect from their cancer. One-quarter of participants reported experiencing six or more late effects.

Because the study did not account for fatigue or sleep disturbances, the actual percentage of survivors who experience late effects from cancer that affect quality of life could be even higher, Huang said.

The next step, Huang noted, is developing a tool kit to help physicians use this information in practice to help [cancer survivors](#) improve their quality of life. Although tools have been devised to make it easier for doctors to measure a patient's quality of life when they visit the doctor, physicians often don't know what to do with this information.

Because of this uncertainty and limited time and staff, only 16 percent of clinicians use quality of life measures in practice, according to a recent national survey Huang conducted on pediatricians' and subspecialists' attitudes and the barriers to assessing pediatric quality of life. Helping physicians calculate and interpret quality-of-life scores and

better use this data to communicate with patients in decision-making processes is important, because the measures take into account health issues that affect patients' day-to-day lives.

"We need to provide clear guidance about quality of life and a different structure to use patient-reported outcomes in clinical settings," Huang said. "The critical step is to develop a methodology to diagnose quality of life of individual [cancer](#) patients or survivors. We are working to develop a diagnostic classification system by focusing on individualized attributes of poor quality of life; symptoms are one of the key, proximal attributes."

Provided by University of Florida

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