

One in Five Cancers Diagnosed in the United States Is a Rare Cancer

Proportion of rare cancers likely to grow as use of molecular markers increases



About one in five cancer diagnoses in the United States is a rare cancer, according to a new American Cancer Society report. The report, [appearing in *CA: A Cancer Journal for Clinicians*](#), a peer-reviewed journal of the American Cancer Society, finds rare cancers account for more than two in three cancers occurring in children and adolescents. The

authors say the proportion of rare cancers is likely to grow as the use of molecular markers to classify cancers increases.

“ In part because of this later stage distribution, 5-year relative survival is poorer for patients with a rare cancer ”

Rare cancers present unique challenges for clinicians and their patients. For most rare cancers, research to identify causes or to develop strategies for prevention or early detection is limited or nonexistent. In addition, rare cancers can be challenging to diagnose, often resulting in numerous physician visits, misdiagnoses, and substantial delays in diagnosis.

Treatment options for rare cancers are often more limited and less effective than for more common cancers, partly because there is less preclinical research and fewer clinical trials for rare cancers, which are often limited to select high-volume cancer centers. Consequently, rare cancers have become an area of priority for some researchers and public health advocates.

There are limited published data on the burden of rare cancers in the United States. Investigators led by Carol E. DeSantis, MPH, used data from the North American Association of Central Cancer Registries and the Surveillance, Epidemiology, and End Results (SEER) program to comprehensively examine contemporary incidence rates, stage at diagnosis, and survival for more than 100 rare cancers (defined as an incidence of fewer than 6 cases per 100,000 individuals per year) in the United States.

They found overall, approximately 20% of patients with cancer in the United States are diagnosed with a rare cancer. Rare cancers make up a larger proportion of cancers diagnosed in Hispanic (24%) and Asian/Pacific Islander (22%) patients compared with non-Hispanic blacks (20%) and non-Hispanic whites (19%). More than two-thirds (71%) of cancers occurring in children and adolescents are rare cancers compared with less than 20% of cancers diagnosed in patients aged 65 years and older.

Among solid tumors, 59% of rare cancers are diagnosed at regional or distant stages compared with 45% of common cancers. In part because of this stage distribution, 5-year relative survival is poorer for patients with a rare cancer compared with those diagnosed with a common cancer among both males (55% vs 75%) and females (60% vs 74%). However, 5-year relative survival is substantially higher for children and adolescents diagnosed with a rare cancer (82%) than for adults (46% for ages 65-79 years).

“Continued efforts are needed to develop interventions for prevention, early detection, and treatment to reduce the burden of rare cancers, write the authors. “Such discoveries can often advance knowledge for all cancers.”

[Article](#): The Burden of Rare Cancers in the United States, Carol E. DeSantis, MPH, Joan L. Kramer, MD, Ahmedin Jemal, DVM, PhD, doi: 10.3322/caac.21400.
