

Research finds identifies social needs of young people with cancer

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Research conducted by Xiao-Cheng Wu, MD, PhD, Associate Professor and Director of the Louisiana Tumor Registry at the LSU Health Sciences Center New Orleans School of Public Health, and colleagues, reports adolescents and young adults with cancer may be at higher risk for social isolation and that a substantial proportion of them have unmet social needs that could adversely affect their health. The research is published online in the *Journal of Adolescent and Young Adult Oncology*. More than 500 participants in the Adolescent and Young Adult Health Outcomes and

[Patient Experience](#) (AYA HOPE) Study completed a survey 6-14 months after diagnosis that included questions about two social information needs – how to talk about their [cancer](#) experience with family and friends and meeting other adolescents or young adult [cancer patients/survivors](#). Patients were identified through seven Surveillance, Epidemiology and End Results (SEER) program sites: the states of Iowa and Louisiana; the metropolitan areas of Detroit, Michigan and Seattle/Puget Sound, Washington; and three metropolitan areas in California: Los Angeles County, San Francisco/Oakland, and Sacramento County. The participants were 15 to 39 years old at diagnosis and were diagnosed with cancers prevalent in that age group. The researchers examined such variables as age at diagnosis, gender, race/ethnicity, education, and health insurance status at diagnosis. They looked at clinical factors including treatment (radiation, chemotherapy, and surgery), current general health, overall quality of care, and the number of symptoms experienced in the previous month. Participants

were asked about the overall impact of their cancer on specific areas of their lives.

The research team found that social information needs were higher among those who were in their 20s at diagnosis – with 25% reporting needing help to talk about their cancer. About 43% of those of Hispanic or "other" race/ethnicity expressed a need to meet peer survivors. Those who were not in a support group, had a high number of symptoms or additional illnesses, as well as low perceived quality of care also needed more help.

"Our findings identify subgroups of adolescents and young adults who are most in need of additional social support and suggest targets for clinical intervention," notes Dr. Wu.

Research has shown that cancer may limit these young patients' ability to form new or maintain relationships at a time in their development when peer bonding is the norm. Even when the patient's support network is strong, current friends may not be able to meet psychosocial needs because they do not understand the problems that come with a cancer diagnosis and treatment, further isolating the patient. Existing resources may be unknown, out of their financial reach, or not relevant to these young people.

Suggested interventions include the development of programs capable of providing support at different phases of the cancer experience, providing services for a diverse age range, overcoming geographic and financial barriers and a lack of cultural diversity in the offerings, as well as increasing awareness and access to peer support groups with other cancer patients and survivors. Improving awareness of and access to online connection through social media, as well as help in learning how to share their experiences with loved ones would also bolster support. The researchers say that developing communication tools specifically for

them may help these young patients express their needs and gain emotional support from their family and friends. It is also important to educate health care professionals and others about these resources.

"With limited research in this area, understanding which subgroups of adolescents and young adults with cancer are most in need and what they perceive their greatest needs to be is critically important to tailor interventions and support programs for them," notes Dr. Wu, who leads one of the 18 cancer registries in the United States designated as SEER registries by the National Cancer Institute.

Provided by Louisiana State University

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