Many Young Adult Cancer Survivors Do Not Seek Follow-up Care After Treatment Ends

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Expert Perspective
“Thanks to decades of advances in cancer treatment for young people, adolescents and young adults who survive cancer today can have a full life ahead of them. But maintaining their health over the course of many years requires attentive follow-up care. This study shows we have work to do to ensure more young adult cancer survivors receive the follow-up care they need,” said ASCO Expert Timothy Gilligan, MD, MSc, FASCO, moderator of today’s presscast.

ALEXANDRIA, Va. – A new study suggests that a large percentage of adolescents and young adults (AYAs) who have been treated for cancer do not seek follow-up care after their primary treatment ends, despite its importance for long-term health. AYA cancer survivors are at increased risk for heart problems, infertility, and secondary cancers from cancer treatment.

Nearly half of those diagnosed between 2005-2009 did not seek a follow-up visit with an oncologist in 2016, while a third of those diagnosed between 2010-2014 did not seek follow-up care that same year. These findings will be presented at the upcoming 2018 Cancer Survivorship Symposium in Orlando, Florida.

“Many adolescents and young adults are unaware of what their long-term risks are after they
have finished their cancer treatment," said lead study author Lynda M. Beaupin, MD, an assistant professor of oncology at the Roswell Park Cancer Institute in Buffalo, New York. "Doctors and other health care providers need to be more diligent in letting these patients know about future potential side-effects and health risks that could occur based on certain aspects of their cancer treatment."

**About the Study**

In a previous study, the authors held a focus group discussion of 27 AYAs, ages 18 to 39, to query them about the major barriers that prevented them from seeking follow-up care. Among the factors some people mentioned were poor communication with their oncologist, ongoing problems in adjusting to life as a cancer survivor, and loss of health insurance.

As a follow-up to that focus group session, the authors looked at a larger group of AYAs who were treated at Roswell Park Comprehensive Cancer Center by using the institute’s tumor registry, which includes any patient diagnosed with cancer within the cancer center. The data collected for the study included de-identified information on a person’s current age, age at cancer diagnosis, gender, date of diagnosis, date of most recent doctor visit, and type of cancer. The most common types of cancer were leukemia/lymphoma, melanoma, germ cell tumors, and thyroid and breast cancers, which are the most common cancer types in this age group.

The investigators divided the AYAs among the top five cancer types into two groups: 852 people diagnosed between 2010-2014 and 783 people diagnosed between 2005-2009. For their analysis they also included patient-provided information on follow-up doctor appointments and insurance status.

**Key Findings**

The length of time since their final cancer treatment visit was the most significant factor in not scheduling a follow-up appointment, with 48% of the people in the 2005-2009 group not having a follow-up visit in 2016 vs. 33% of those in the 2010-2014 group not having a visit in 2016. The type of cancer they were treated for did not make a difference in whether a follow-up visit was sought. While health insurance played no role in determining whether the people in the 2005-2009 group sought a follow-up visit, slightly more people without insurance did
not schedule follow-up appointments than people with health insurance (39% vs. 33%) in the 2010-2014 group, but that difference was not statistically significant.

**Next Steps**

The researchers hope to look at other factors that may affect the willingness of AYAs to seek follow-up care in future studies, such as employment status, distance to a cancer center, whether they are getting tested or treated at a facility other than a cancer center, and perhaps most importantly, note the authors, how AYAs perceive their current quality of life.

“These patients have the potential to live a normal lifespan, and we need to educate them to become their own advocates so they may receive follow-up care on a regular basis,” said Dr. Beaupin. “We hope they continue to receive that follow-up at an established cancer center that has the facilities to assess cardiac health and provide rehabilitation if needed. There are now established survivorship programs nationwide that can provide follow-up care for those who have completed treatment.”

The researchers would like to have access to larger databases such as those maintained by health insurance providers in order to conduct more comprehensive studies. They are currently in contact with several providers to determine if there is a secure way to obtain those data.

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View the full abstract.

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