

Young adult survivors most distressed after leukemia and lymphoma treatment

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“Now that patients are living longer with cancer and after cancer, it is becoming more and more important to look at how survivors are living. What is their quality of life and how can we help make it better?” says Whitney Jones, PhD. Credit: Flickr/ Misha Dontsov cc license

Two University of Colorado Cancer Center studies published in the *Journal of Psychosocial Oncology* show that young adult survivors (ages 18-39) of leukemia and lymphoma are more likely to report high distress than older survivors (ages 65+). Specifically, 45 percent of younger patients report moderate-to-high distress, whereas only 18 percent of older patients report similarly elevated levels. Interestingly, in both

groups this distress was not affected by time since treatment - distress was just as likely to be high in survivors who had completed treatment four years prior as in survivors who were three months out of treatment.

"Now that patients are living longer with [cancer](#) and after cancer, it is becoming more and more important to look at how [survivors](#) are living. What is their quality of life and how can we help make it better?" says Whitney Jones, PhD, the studies' first author, working with data collected by Carly Parry, PhD, research scientist at Kaiser Permanente, California. Both Jones and Parry are family members of cancer survivors. Jones says, "It was natural - I just kind of fell into survivorship research."

Jones explains the effect of age on distress using a framework called the Lifespan Perspective. Because there is an expected social, cultural and developmental course of a person's life, an event (such as cancer) that is highly disruptive in one lifespan stage may be less disruptive in another.

"For younger survivors, cancer is out of context," Jones says. "When you're under forty, you're finishing your education, entering the workforce, starting a family, and cancer may be interpreted as disruptive and unexpected in that phase. On the other hand, some of our older survivors said things like, 'Cancer isn't the most difficult thing I've experienced in life.' And they knew friends and family members who had dealt with similar cancer experiences," she says.

One paper surveyed 477 cancer survivors, using a widely-used measure of distress after trauma and several items from a measure of quality of life in cancer survivors. These measures allowed Jones, Parry and colleagues to ask which factors of a [cancer survivor](#)'s life after treatment are the best predictors of persistent distress after treatment completion. Survivors under age 40 had the highest prevalence of distress, while a risk profile showed that a person's fear of cancer recurrence was the best

predictor of elevated distress - people who feared recurrence were most likely to also report high overall distress levels. High financial burden due to [cancer treatment](#) also predicted distress.

The second study used interviews with 51 leukemia survivors to explore the human side of these numbers and better understand the sources of distress as articulated by survivors themselves.

"For example, this was before the Affordable Care Act, and we had one survivor who talked about having only the basic college student insurance when he was diagnosed. After treatment he discovered he had substantial medical debt and was uninsurable. It helped to hear survivors talk about their experiences in their own words. To hear them articulate it helped us understand the real struggles behind our data," Jones says.

Interviews may also help explain why distress lingers even years after treatment ends.

"A patient told us that, after lymphoma treatment, her doctor said that it would take two years to recover physically and mentally, and that almost all the gains would be in these two years," Jones says. "She said something like, 'I was really patient for two years, then after those two years passed, I didn't feel any better and realized this is what I was going to be living with.'"

Distress detection and treatment is increasingly being seen as part of the standard of care for cancer patients and post-treatment survivors. For example, organizations like the National Comprehensive Cancer Network (NCCN) and the American College of Surgeons Commission on Cancer (ACS CoC) mandate distress screening and [treatment](#) in order to earn accreditation from these institutions.

"Understanding which individuals are most likely to experience elevated

distress," for example young adult survivors who report fear of recurrence and financial strain due to cancer, "can be useful in targeting interventions to potential participants," Jones says.

Provided by University of Colorado Denver

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