For Young People with Advanced Cancer, Study Finds Serious Communication Gaps about Their Care

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April 16, 2025 By National Cancer Institute

Many adolescents and young adults (AYAs) with advanced cancer don't have discussions with their clinicians about how they want to approach palliative care until the final weeks of life, a study of medical records of nearly 2,000 young patients showed.

The researchers also found that, as of more than 2 months before their deaths, few AYAs in the study had documented goals for care of any kind in their medical records, including things such as how aggressive they would like to be with their cancer treatments.

The findings come from an NCI-funded study that analyzed how documented discussions between AYA patients with advanced cancer and their providers about the goals of care change over the patients' last few months of life. The study results were published December 19 in JAMA Network Open.

Talking about care and treatment near the end of life is one of the most challenging aspects of caring for AYAs with advanced cancer, said Ashley Wilder Smith, Ph.D., M.P.H., of NCI's Healthcare Delivery Research Program and co-leader of NCI's Adolescent and Young Adult Oncology Working Group. The results of this new study provide important insights for clinicians and patients to consider, Dr. Smith added.

"When a young person is faced with a disease that may lead to an early death, it's vitally important to give them the opportunity to think about what's most important to them and what happens to them in terms of care in the time they have left," she said.

No roadmap for AYAs navigating incurable illness

About 84,000 people aged 15 to 39 years received a cancer diagnosis in the United States in 2024. And although many AYAs with cancer survive the disease, with about 86% living for 5 years or longer from the time of their diagnosis, an estimated 8,900 died from their cancer last year.

“The individual is experiencing an incurable illness and they and their family don’t have a roadmap for how they should be navigating it,” Dr. Smith said, noting that death in young people, when it happens, is usually from an accident or injury. “We don’t expect young people to die, and existentially it’s not something they’re expected to think about.”

Previous research has shown that AYAs with cancer often receive medically intensive care at the end of life, which may not help them live longer but can worsen their quality of life.

That’s why documenting goals of care is so critical, so clinicians can be aware of how an AYA’s preferences can be understood and respected, said Lori Wiener, Ph.D., of NCI’s Pediatric Oncology Branch and an investigator on the study.

Discussing care goals increased as the end of life neared

To conduct the study, the researcher team analyzed medical records for more than 1,900 people aged 12 to 39 at the time of their death from cancer. All had been treated at Dana-Farber Cancer Institute or one of two Kaiser Permanente health systems in California.

The researchers looked specifically for documentation of discussions that patients had with their health care teams during the last 3 months of their lives about their care goals—that is, what kind of treatment they wanted and how they wanted to manage pain and other symptoms—and how those goals changed during that period.

The discussions were categorized as occurring in the early (61–90 days), middle (31–60 days), or late (30 days or fewer) periods before death.

More than 70% of people whose records were examined had no documented discussions about their care goals in the early period. By the middle period, slightly fewer than half had documented discussions about their goals of care, and in the last month of life, more than 80% had documented discussions.

Palliative care as a goal

One focus of the study was on the preference for palliative care, which is care intended to improve the quality of life by addressing the physical and psychological symptoms of cancer and its treatment.

Patients expressing a preference for palliative care increased from about 7% in the early period to about 17% in the middle period and to nearly 58% by the last month of life.

For many in the study, goals-of-care discussions didn’t occur until the last month of life, and those discussions were mostly expressing a desire for palliative care.

“A lot of patients in this study talked about their palliative care preferences when first asked about

their care goals, but those discussions didn't occur until the patients were close to the end of their lives," said Dr. Smith. "It's possible they may have had different goals earlier in their disease course, or they may have wanted palliative care earlier, but there's no way to tell without those documented discussions."

Palliative care can be used at any point during cancer treatment, she continued, including during treatment intended for cure or intended to meaningfully extend life.

"There's a misconception, even among many clinicians, that palliative care is just for the last few weeks of life," Dr. Smith said.

Documented discussions influenced care

Documenting care goals also influenced the kind of end-of-life care that patients received. For example, those people who expressed a desire for palliative care in the early period were less likely to receive treatment in an intensive care unit in the last month of life.

Likewise, people who received palliative care in the early period had fewer emergency room visits and hospitalizations in the final month of life than those who first discussed palliative care in the last month of life and those who had expressed goals that did not include palliative care.

That these discussions did influence the care people received shows why "it's really important to have conversations about [goals of care] early and to have them often," Dr. Smith said.

Documenting goals of care is essential

Although discussions about care may occur informally between a patient and their health care team, it's important that these discussions be documented in health records, Dr. Wiener stressed.

"Documentation of conversations about goals of care is one of the most fundamental steps clinicians can take to ensure that the care provided reflects what's most important to the patient: that it meets their needs and aligns with their preferences and their values," she said.

For example, if a person tells their doctor they don't want to go into the ICU again, documenting that discussion will let other doctors who may care for the patient know their preference.

"It allows what's most important to the patient to be honored, especially when they're critically ill," Dr. Wiener said.

Discussions about care may extend beyond treatment

In addition to documenting goals of care, these discussions should also include topics that reflect how patients want their values honored if they were to get sicker, Dr. Wiener said.

“These conversations should address how the person would like to be supported [and] how they would like to be comforted,“ she said. ”Who do they want with them during appointments or treatment? Who would they want to be present as they face their final days? How do they want their family and friends to remember and memorialize them?”

Another consideration is where they want to spend their last days.

In another recent article by the same research team, about 63% of AYAs with cancer studied in the Dana-Farber–Kaiser Permanente cohort had documented discussions about where they preferred to die: at home, in a hospital, or at a hospice facility. Of those who had discussed a possible location of death, nearly half did not express a preference, and more than 32% preferred to die at home.

Are clinicians doing enough to give dying AYAs a voice?

Both studies found that documented discussions about these important issues often didn’t happen until the last month of life. The findings suggest that clinicians may not be doing enough to raise these end-of-life issues with their AYA patients, Emily E. Johnston, MD, from the University of Alabama at Birmingham, and Jennifer M. Snaman, MD, of Dana-Farber Cancer Institute wrote in an editorial that accompanied the study about where AYAs with terminal cancer wished to die.

“Did clinicians’ lack of comfort in having goals of care conversations lead them to not engage in these discussions? Did these conversations occur but were not documented? Did clinicians not engage AYA patients in discussions around [location of death] preferences because they believed that death outside of the hospital was unlikely?” they wrote.

AYA-specific conversation tools are being developed and tested, they explained, including video-based tools and guides modified from those used with pediatric patients. They pointed to one tool, called Voicing My Choices, as a way to help structure and document a wide variety of end-of-life care preferences.

Voicing My Choices

Voicing My Choices™ is a planning guide for young people living with a life-limiting illness and for those at the end of life. Developed by NCI’s Pediatric Oncology Branch, the guide was created with input from AYAs with advanced cancer and other serious illnesses. A 2022 study found that AYA patients who completed the guide experienced less anxiety and were more likely to discuss their end-of-life goals with family members. Most of those who did share their thoughts with family reported they likely would not have done so had they not participated in the study.

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