

Studies focus on teens, adults at end of life

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A related package of articles published online by *JAMA Oncology* focuses on end-of-life care for teens and young adults and advance care planning for patients with cancer. The package of articles includes two original investigations, an invited commentary, an editorial, an accompanying editor's note and an author audio interview.

End-of-Life Care for Teens, Young Adults with Cancer

In the first study, corresponding author Jennifer W. Mack, M.D., M.P.H., of the Dana-Farber Cancer Institute, Boston, and her coauthors looked at the intensity of [end-of-life care](#) for teens and young adults who died between the ages of 15 and 39. The study analyzed Kaiser Permanente Southern California cancer registry data and electronic health records for 663 adolescents and young adults with either stage 1 to stage 3 cancer and evidence of cancer recurrence or stage 4 cancer at diagnosis. All patients died between 2001 and 2010.

The most common cancer diagnosis was gastrointestinal cancer, while other common diagnoses were breast cancer, genitourinary cancers, leukemia and lymphoma.

The authors found that 11 percent of patients (72 of 663) received chemotherapy within 14 days of death; in the last 30 days of life, 22 percent of patients (144 of 663) were admitted to the [intensive care unit](#); 22 percent of patients (147 of 663) had more than one emergency department visit; and 62 percent of patients (413 of 663) were

hospitalized. Overall, 68 percent of patients (449 of 663) received at least one medically intensive end-of-life care measure.

The authors note their findings may not reflect care for the wider U.S. population.

"Although adult patients who know they are dying usually do not want to receive aggressive care, which is associated with poorer quality of life near death, we do not know whether AYA [adolescents and [young adults](#)] feel the same way. High rates of intensive EOL [end-of-life] measures in this population may not be a failure of communication or palliative care but might reflect very different values for EOL care in these young people compared with older adults. ... However, our data provide a starting point for understanding patterns of care and ultimately defining optimal EOL care in this young population. Ongoing work should focus on understanding EOL care needs and preferences in this young population," the study concludes.

Trends in Advance Care Planning in Patients with Cancer

In a second study, Amol K. Narang, M.D., of the Johns Hopkins School of Medicine, Baltimore, and coauthors examined trends in advance care planning with durable power of attorney (DPOA) assignment, the creation of living wills and discussions of EOL care preferences.

The authors analyzed survey data from 1,985 next-of-kin surrogates, who were mainly partners or spouses or children, of Health and Retirement Study participants with cancer who died between 2000 and 2012. About 81 percent of those patients who died had engaged in at least one form of [advance care](#) planning.

Results indicate that from 2000 to 2012 there was an increase in DPOA assignment (52 percent to 74 percent) but not significant change in the use of living wills (49 percent to 40 percent) or EOL discussions (68 percent to 60 percent).

Reports from surrogates that patients received "all care possible" at the end of life increased during the study period from 7 percent to 58 percent, although rates of terminal hospitalizations were unchanged (29 percent to 27 percent), the study reports.

The limiting or withholding of treatment was associated with living wills and end-of-life discussions but not with DPOA assignment.

The authors note a limitation of their study is that information on [advance care planning](#) and EOL treatment decisions came from proxies and not the patients.

"Without written or verbal direction, surrogate decision makers may struggle to make care decisions consistent with patient preferences. As such, policy and health system initiatives that support wider adoption of clinician-patient discussions of EOL care preferences are essential. In addition, these conversations must also include [surrogate decision makers](#): efforts to educate surrogates on the goals, values and care preferences of their loved ones have proven valuable across multiple chronic diseases and should be further explored in [patients](#) with advanced [cancer](#)," the article concludes.

More information: *JAMA Oncol.* Published online July 9, 2015. [DOI: 10.1001/jamaoncol.2015.1953](https://doi.org/10.1001/jamaoncol.2015.1953)

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