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Cost of Cancer in Adolescents and Young Adults in the United States: Results of the 2021 Report by Deloitte Access Economics, Commissioned by Teen Cancer America

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abstract

PURPOSE The purpose of this report, commissioned by Teen Cancer America and performed by Deloitte Access Economics in 2021, was to estimate the total costs incurred by adolescent and young adults (AYAs) after cancer diagnosis in the United States (US) over their life course.

METHODS The incidence of cancer in 2019 among AYAs age 15-39 years was estimated from the US Cancer Statistics Public Use Database, and relative survival was projected from the Surveillance, Epidemiology, and End Results Program. Cost domains included health system, productivity, and well-being costs. Components were estimated with published literature and pooled data from the Medical Expenditure Panel Survey from 2008 to 2012 and inflated to 2019 dollars.

RESULTS The economic and human costs of cancer in AYAs are substantial—$23.5 billion overall, corresponding to $259,324 per person over the lifetime. The majority of costs are borne by AYA cancer survivors themselves in the form of lost productivity, loss of well-being, and loss of life.

CONCLUSION These findings underscore the need to address the burden of cancer in AYAs through targeted programs for AYAs, such as financial navigation and health insurance literacy interventions, as well as local and national policy initiatives to address access to and enhanced coverage for clinical trials participation, fertility services, and survivorship care.

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BACKGROUND

Each year nearly 90,000 adolescents and young adults (AYAs), age 15-39 years, are diagnosed with cancer, accounting for approximately 5% of all new cancer cases in the United States (Data Supplement, online only [Supplement Table 1]).[1] The concerted efforts over the past two decades by leaders in AYA Oncology, including clinicians, researchers, advocates, patients, and caregivers, have resulted in increased awareness of cancer among AYAs within the broader cancer community. In response to the historically worse outcomes for this age group as compared with younger *or* older patients, the so-called AYA gap,[2,3] AYA-specific clinical and survivorship programs have been developed,[4,5] along with increasing numbers of clinical trials offered across the pediatric- and adult-based groups.[6] With prompt diagnosis and timely delivery of appropriate therapy, the majority of AYAs with cancer[7] have excellent prognosis; in 2019, the 5-year relative survival rate was 85%.[8] Although AYA death rates have fallen each year between 2010 and 2019,[8] gaps in our knowledge about the impact of cancer to this vulnerable population remain. One of most striking gaps is our understanding of the economic consequences of cancer diagnosis and treatment both during and beyond the AYA years. A greater understanding of the economic consequences of cancer is critical given the developmental timing of the cancer diagnosis, prevalence of uninsured and underinsured, and low health literacy in this population,[9,10] coupled with the growing costs of cancer treatment in the United States.

Cancer within the AYA age group has important developmental implications. Late adolescence and young adulthood are times of educational and vocational attainment. Cancer can result in interruption of formal education[11] and employment loss or lock[12,13] with the latter referring to reluctance to change jobs to ensure continued access to employer-based benefits, including health insurance coverage and paid sick leave. For some AYAs, the initial diagnosis and treatment result in an interruption of ongoing plans while for others the trajectory is permanently altered.[11] At the same time, AYAs with cancer face additional costs not borne by older patients with cancer, such as from oncofertility

ASSOCIATED CONTENT

Data Supplement

Author affiliations and support information (if applicable) appear at the end of this article.

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CONTEXT

Key Objective

The purpose of this article was to use best available data and state-of-the-art methodology to estimate the total costs incurred by adolescent and young adults (AYAs) with cancer over the life course.

Knowledge Generated

The 2021 Cost of Cancer report, commissioned by Teen Cancer America and performed by Deloitte Access Economics, outlines the considerable cost incurred by AYAs with cancer in the United States, highlighting the relatively large burden of cost on the patients themselves in the form of lost productivity, loss of well-being, and loss of life (premature mortality). The report also describes the limitations in currently available data and proposes solutions for improving our understanding of the financial burden of cancer in this age group.

Relevance *(J.W. Friedberg)*

This report demonstrates the complexities involved in obtaining oncology cost data for the AYA population. National registry efforts in this population should prioritize prospective collection of data addressing economic burden of cancer.*

*Relevance section written by *JCO* Editor-in-Chief Jonathan W. Friedberg, MD.

care, which is typically not covered by health insurance. Financially, this can translate to escalating medical debt,[14] lost opportunity to build savings,[15] and reduced access to affordable, quality health insurance coverage.[16,17] Adult patients with cancer (18-64 years) experienced higher material, psychological, or behavioral financial hardship than adults older than 65 years.[18] In a 2012 study by Banegas et al,[14] one third of recently diagnosed cancer survivors age 18-64 years experienced medical debt, and 3% had filed for bankruptcy. A 2022 survey by the Kaiser Family Foundation on medical debt reported that 41% of US adults, more than 100 million in total, experienced debt with 17% reporting bankruptcy or home loss. This survey also concluded that chronic illness was a stronger predictor of medical debt than poverty or insurance status.[19] Studies have shown that cancer survivors filing for bankruptcy protection were more likely to be younger[20] and had increased mortality risk compared with similar survivors without financial hardship.[21]

AYAs also have been historically among the highest uninsured/underinsured age groups,[22,23] largely because of inability to access the largely employer-sponsored private health insurance system common in the United States. Furthermore, changes in types of employers and generosity of benefits over the past couple of decades affect current AYAs who may be more likely to be gig economy workers or to work in positions without benefits. The passage of the Patient Protection and Affordable Care Act (ACA) has three important provisions that were critical for AYAs: (1) the Dependent Coverage Expansion with extended coverage under parents' private insurance until 26 years; (2) elimination of the ability to deny coverage or charge more or due to a preexisting condition; and (3) increased access to insurance through Medicaid expansion in some states and creation of health insurance exchanges (Marketplace)[24-30] for individual purchase with premium subsidies. Among those states that elected to expand Medicaid income eligibility to residents, there has been an increase in insurance coverage and detection of early-stage cancer (*v* late stage) among AYAs.[29] In addition to improved access to health insurance coverage, recent data have demonstrated after the enactment of ACA that earlier stage at diagnosis[29] increased 2-year relative survival, especially among patients age 19-23 years. Improved survival was noted among those of Hispanic ethnicity and among those of lower socioeconomic status.[31] Yet, even with the ACA, AYA survivors compared with adults without cancer report a greater likelihood to delay or forgo care because of cost and higher cost-related nonadherence to prescription medications.[32]

In this article, we report on the results of a report commissioned by Teen Cancer America (TCA), an AYA-focused, US-based charitable organization, in conjunction with its assembled scientific advisory board. The purpose of the 2021 report, titled The Cost of Cancer in AYAs in the United States of America (Cost of Cancer),[33] performed by Deloitte Access Economics, was to use best available data and state-of-the-art methodology to estimate the total costs incurred by AYAs with cancer over the life course. Furthermore, by highlighting the economic burden to patients and their families, the health care sector, and society, TCA sought to demonstrate the value of dedicated AYA-based care. We end with a summary of the clinical and policy implications of these findings.

METHODS

The Cost of Cancer report[33] was inspired by a similar report produced by Deloitte in Australia for Canteen (a charity organization in Australia), addressing the needs of patients age 12-25 years with cancer.[34] However, unlike the United States, Australia has a universal health care

TABLE 1. Types of Costs and Methodology

Cost Component	Data Source	Analytic Approach	Limitations	Comments
Health system costs Hospital Out-of-hospital pharmaceuticals Cost by payer	Pooled data from MEPS: 2008-2012.[35] Fertility data drawn from literature.[36]	Phase-of-care approach; inflated to 2019 dollars.	Underrepresentation of rare or poor prognosis cancers; cannot identify end-of-life costs; sample insufficient to do cost/individual diagnosis types.	Nationally representative sample of 447 unique AYAs with cancer and 641 complete years of data with comparisons with general population about 12 cancer types. Fertility estimates in Katz study[36] restricted to an 18-month prospective cohort of 400 AYAs.
Productivity costs Absenteeism Presenteeism Reduced rates of employment Premature mortality Impact on informal caregivers	Literature scan by topic; registry-based study,[37,38] Estimates from Society for Human Resource Management; Work Ability Index;[39-41] reduced employment rates/workforce participation by cancer type for men and women. Work and school participation estimated from the NCI AYA HOPE Study.[11] Premature mortality cost: product of survival rates by cancer type and the expected remaining lifetime earnings (weighted against probability of being employed by age and sex).	Published literature and results of validated tools, estimates by cancer type and compared with general population. Replacement cost method used, monetizing time for volume of hours worked by hourly rate of replacing this informal caregiver's effort with paid care. Used results from literature about hours worked.[42,43]	Data on relative rates of sick leave obtained from the 2012 study by Torp et al.[38] Sick leave policies in Norway are likely to be different than those in the United States.	Type of productivity loss varies by cancer type, ability to participate in workforce, and overall mortality. Cancers with high case fatality rates and low employment rate will have lower absenteeism and presenteeism, but higher losses due to premature mortality. Total productivity cost from premature mortality highest among AYA with cancers with high incidence and mortality (eg, brain, leukemia, colorectal) versus those with lower mortality (eg, thyroid).
Loss of well-being	2019 data from Institute of Health Metrics and Evaluation;[44] OMB;[45] WHO.[46]	Calculation of DALYs by cancer type and sex. Monetized to yield Value of Statistical Life Year.		Calculations also take into account relationship between incidence and age.
Other costs (transfer): payments SSI/SSDI Forgone individual taxes Forgone corporate taxes Government expenditures	Literature review; reports from governmental agencies and tax foundation.			Shift in resources from one entity to another. From an economics perspective, these shifts create inefficiencies and distortion in the economy (known as dead weight loss).

Abbreviations: DALYs, disability-adjusted life years; MEPS, Medical Expenditure Panel Survey; OMB, Office of Management and Budget; SSI, supplemental security income; SSDI, social security disability insurance.

system and national registries on cancer costs by age group; thus, producing a comparable report in the United States was far more challenging and required broader reach and guidance. To define the goals of the report and its scope, TCA assembled a multistakeholder panel, representing AYA clinicians, program leaders, researchers, and advocates across the United States; please see supplement for full listing of stakeholder panel members. TCA Executive Director (S.J.D.) and principal investigator (S.K.P.) met regularly with the advisory practice from Deloitte Global Economics to review the primary and secondary questions, define potential sources of data, and review interim and final results. The report was then reviewed and formally critiqued by the coauthors, all topic experts in health outcomes and AYA oncology.

We summarize the costs associated with the health system, productivity losses, loss of well-being, and other financial aspects (also known as transfers; Fig 1; Table 1). Readers are urged to review the report[33] in its entirety, given the range of data sources and methods used.

Health System Costs

These costs were estimated using a phase-of-care approach from pooled data from the Medical Expenditure Panel Survey (MEPS) from 2008 to 2012 because of data availability by age[35,47] and inflated to 2019 dollars. Phase-of-care cost estimates typically follow a U-shaped distribution with high cost during the initial phase of treatment and at the end of life. Although MEPS data provide a reasonable estimate of initial health system expenditure, they cannot be reliably used to estimate end-of-life costs, given the cross-sectional nature of the survey. In addition to a lack of longitudinal data, MEPS underrepresents costs associated with rare cancers or those with high case fatality rates that may have higher costs than their newly diagnosed counterparts with other cancers.

Furthermore, MEPS data do not include costs associated with screening programs, public health initiatives, or oncofertility. Given the salience of the latter costs in AYA oncology, the report relied on estimates of the cost of fertility preservation by sex, on the basis of treatment costs reported by the Alliance for Fertility Preservation[48] and assumptions about the uptake of the procedures.

Prescription drug costs in this report were also estimated from MEPS but were restricted to costs incurred in the out-of-hospital setting (eg, ambulatory/outpatient or home) and excluded specific out-of-pocket costs associated with prescription drugs. Pharmaceutical costs associated with inpatient and emergency department use were bundled in MEPS with other hospital costs.

Productivity Costs

Productivity cost varies by cancer type and by phase of illness. Much of the absenteeism-associated costs are incurred within the first year of illness, often during active treatment. Importantly, absenteeism-associated costs are borne when the patient with cancer is still able to continue working. Absenteeism was estimated in this report by combining data on work loss days with relative rates of sick leave use—both within the first 5 years of cancer diagnosis.[37,38] Little information is available about absenteeism rates or costs beyond 5 years.

Presenteeism captures reduced performance due to fatigue, mental strain, cognitive dysfunction, or persistent symptom burden. Presenteeism costs are borne by individuals who are still able to work, albeit with altered performance. Several validated measures are now available to estimate presenteeism, including the Work Ability Index,[49]

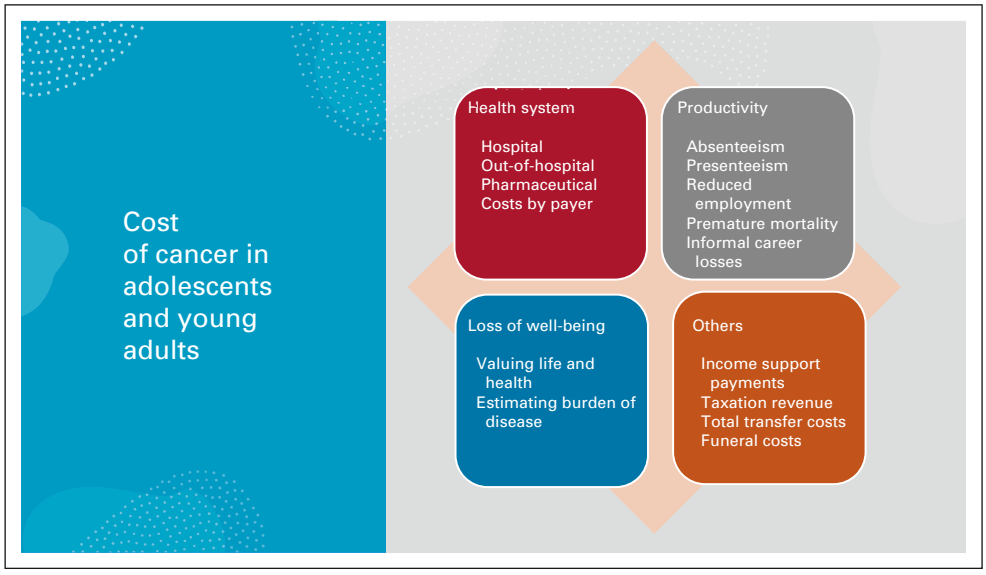

FIG 1. Cost of cancer in adolescents and young adults.

the Work Performance and Activity Impairment scale,[50] and the Work Limitations Questionnaire.[51] To monetize the impact of presenteeism, the degree of impairment is expressed as a percentage which can then be multiplied by wage scales to generate a cost. For the Cost of Cancer report,[33] data from two studies with population-level comparative data were combined to estimate a 5-year profile of cancer-related presenteeism, on the basis of the Work Ability Index.[39,40] This profile showed highest levels of presenteeism in the first year of diagnosis among AYAs, with attenuation after the second year.

Productivity costs associated with individuals who have stopped working because of treatment or death are accounted separately, either as reduced workplace participation and/or premature mortality. Guy et al found a 66.6% workplace participation among 1,464 AYA cancer survivors compared with 72.6% in individuals without a history of cancer.[52] The cost of reduced workplace participation varied by cancer type with the highest per-person costs for brain cancer.

The cost of premature mortality is estimated to be highest among those cancers with high incidence and mortality, including brain, breast, and colorectal cancer, as well as leukemia. In this report, premature mortality was monetized to capture lost wages over the lifespan. The cumulative financial cost of lost wages can vary by the assumptions used. One commonly used approach is to rely on the US national average wage index (AWI), published annually by the Social Security Administration. In 2020, for example, the AWI was $55,629.[53]

Data on the cost of informal caregiving are sparse. In this report, replacement cost methods were used in which the informal caregiver's efforts were replaced with the cost of paid care. In this report, unpaid caregiver time was replaced with the hourly wages of a home health aide. Two studies provided estimates of total hours worked.[42,43]

Loss of Well-Being

The metric used to estimate loss of well-being, disability-adjusted life years (DALYs), calculated as the sum of years of life lost because of premature death (years of life lost) and the years of health lost because of disability (years lived with disability or impaired health). Disability weights can be assigned by health state on a scale of 0 for perfect health and a value of 1.0 for death. In the example provided by the Cost of Cancer report,[33] using 2019 data from the Institute of Health Metrics and Evaluation,[44] a disability weight of 0.2 means a 20% loss in well-being relative to perfect health for the duration of the condition. Of note, specific disability weights are not currently available for specific late effects risks, likely underestimating the impact of treatment-related sequelae. In a worldwide estimate, published in 2022 by the Global Burden of Disease (GBD) Study 2019 AYA Cancer Collaborators,[54] AYA cancer accounted for the fourth leading cause of death and the tenth leading cause of disability, expressed as DALYs, in AYAs globally.

Other Costs

This category of cost includes shifts in resources from one sector to another, including components such as forgone taxes or income payments from employers to government-sponsored disability program. From an economics perspective, these create system inefficiencies or distortion.

RESULTS

Health System Costs

The health system bears 13.7% ($3.2 billion) of the financial cost of AYAs with cancer with approximately half of this amount (44.9%) incurred by the hospital sector, 38.1% outside of the hospital, and nearly 12% by prescription drugs (Table 2). Fertility preservation accounted for 4.9% of the health care costs, with average costs ranging from $331 for men to $1,810 for women. Insurance coverage for fertility preservation varies considerably by state. Lack of long-term data precluded estimates of the cost of fertility restoration; however, these costs can be considerable, depending on the treatment used, particularly if surrogacy is required. The bundled cost of medical, legal, and agency fees associated with surrogacy can exceed $150,000 per pregnancy.

Productivity Costs

The total productivity costs of AYAs with cancer diagnosed in 2019 were estimated to be $18.03 billion over their lifetime with more than half of these costs due to premature mortality ($10.8 billion), driven by the relatively young age at death (Table 3). Reduced workforce participation was the next largest cost ($2.5 billion) because of the significant impact that a cancer diagnosis has on an individual's capacity to remain in employment. Absenteeism and presenteeism combined were responsible for $1.6 billion.

TABLE 2. Estimated Lifetime Health System Costs of Cancer

Health System Component	Total Cost, $ Millions	Per-Person Cost, $	Proportion of Costs, %
Hospital	1,448.2	15,985	45
Out-of-hospital	1,386.6	15,305	43
Pharmaceuticals	384.6	4,245	12
Others	3.6	40	<1
Total	3,223.1	35,575	100

NOTE. Totals may not add because of rounding. Source: Deloitte Access Economics, Cost of Care report.[33] Calculations on the basis of US Cancer Statistics SEER Database (2019)[55] and MEPS data (2019).[35]

Abbreviation: MEPS, Medical Expenditure Panel Survey.

TABLE 3. Summary of Productivity Costs by Component

Component	Total Cost, $ Millions	Per-Person Cost, $ Thousands
Absenteeism	506.8	5.6
Presenteeism	1,102.7	12.2
Reduced workforce participation	2,542.2	28.1
Premature mortality	10,816.4	119.4
Informal care	2,365.5	26.1
Employer administrative costs	696.6	7.7
Total	18,030.2	199.0

NOTE. Columns may not add due to rounding. Source: Deloitte Access Economics, Cost of Care report.[33]

Loss of Well-Being

The loss of well-being was estimated to be $96 billion, at an average cost of $1 million per person over their lifetime (Table 4). Because the rates of diagnosis increase with age within the AYA age span, well-being costs are highest for AYAs diagnosed in the 35-39 years age group.

Other Costs

Other costs (transfers) were not as high as the aforementioned components, but still represented as a total of $2.2 billion among AYAs diagnosed in 2019. The majority of this efficiency loss was the result of forgone income and associated taxation, at 76% of the total loss. Government health expenditure accounted for 12%, with company tax (8%) and welfare payments (4%) being the smallest contributors.

In summary, on the basis of 2019 estimates, the current and future financial cost of AYAs with cancer in the United States was $23.5 billion, corresponding to a lifetime cost of $259,324 per AYA with cancer (Table 5). Although the majority of health system costs were covered by private payers (61%), the majority of total costs (70%) was borne directly by AYAs with cancer and their families with the greatest burden of cost due to productivity loss (ie, the loss of work or revenue). Productivity-related costs accounted for $18.3 billion dollars with a per-person lifetime cost of $199,000. Premature mortality and lifelong loss of well-being due to morbidity are amplified by the impact of young age and diagnosis.

TABLE 4. Total Well-Being Costs for all AYAs With Cancers, by Age and Sex

Age, years	Male, $ millions	Female, $ millions	Total, $ millions
15-19	4,566.9	2,819.5	7,386.4
20-24	6,227.2	4,301.5	10,528.7
25-29	8,883.8	8,134.1	17,017.8
30-34	11,167.5	13,389.7	24,557.2
35-39	14,902.2	21,648.1	36,550.3
All ages	45,747.5	50,292.9	96,040.5

NOTE. Source: Deloitte Access Economics, Cost of Care report.[33]
Abbreviation: AYAs, adolescent and young adults.

TABLE 5. Total Cost of AYAs With Cancer, by Component

Component	Total Cost, $ millions	Per-Person Cost, $ Thousands
Health system	3,223.1	35.6
Productivity	18,027.6	199.0
Other financial	75.7	0.8
Efficiency loss (proportion of transfer costs)	2,168.4	23.9
Total financial costs	23,494.8	259.3
Burden of disease (nonfinancial)	96,040.5	1,060.0
Total	119,535.3	1,319.4

NOTE. Totals may not add because of rounding. Source: Deloitte Access Economics, Cost of Care report.
Abbreviation: AYAs, adolescent and young adults.

DISCUSSION

Given the current financial climate including the adverse economic effects of the COVID-19 pandemic, rising inflation, and unstable employment, the situation for AYA cancer survivors is likely to remain precarious. The economic and human costs of cancer in AYAs are substantial, with the majority of costs borne by AYA cancer survivors in the United States themselves in the form of lost productivity, loss of well-being, and loss of life. The Cost of Cancer report[33] results support the need to advocate for better treatment and access to care to reduce mortality rate in AYAs with cancer. AYAs will directly benefit from continued research on effective treatments, prevention strategies, and comprehensive insurance coverage options to ensure that adequate surveillance and health maintenance are affordable.

Data are also needed to better understand the impact of location of care on both patient and caregiver productivity among AYAs. Although there have been recent strides in shifting care away from the inpatient setting to either outpatient or home-based care, care and cost shifts are now borne more by the patient and caregivers and may contribute to elevated stress, out-of-pocket expenses, and work/income loss. Additional research is needed to fully characterize the spillover cost of informal caregiving across cancer types, phase of care, and patient ages.[56]

Across selected diagnoses, particular attention is needed to understand the impact of prolonged maintenance therapy, chronic treatment with novel oral agents, and use of risk reduction strategies, such as hormone therapy for breast cancer, on AYA costs. Specifically, it is critical to understand treatment side effect profiles and the impact of treatment on patients' work ability/work force participation. In addition to cost of these agents, particularly out-of-pocket costs, persistent side effects may contribute to absenteeism, presenteeism, or reduced work force participation. Furthermore, improved longitudinal data are

needed to accurately reflect the loss of well-being, along with the functional consequences of cancer and its sequelae. This includes information on the impact of chronic symptoms, such as persistent fatigue or chronic pain,[57] as well as disabling late effects that occur beyond the typical follow-up from clinical trials in which only a minority of AYAs participate.[58] For AYAs, functional consequences need to broadly consider school and work participation, both as measures of role functioning, in addition to physical, social, and emotional functioning.

One of the most striking findings in preparing the Cost of Cancer report[33] is the limitation of available data on the totality of the cancer experience for all patients, especially for AYAs. Although cross-sectional data from MEPS offer important insights, data are sparse across selected cancers and longitudinal data beyond 2 years in racially/ethnically, and sociodemographically diverse populations are not available. As highlighted in the report, neither fertility preservation nor restoration costs are captured in MEPS. Initiatives, such as the Children's Oncology Group's (COG) Umbrella Long-Term Follow-up Protocol (ALTE05N1), provide an important mechanism for long-term follow-up on selected COG clinical trials; similar information is not available for survivors not treated on COG trials, especially older AYAs. Therefore, it may be time for the creation of a US-based AYA national registry with consistent follow-up across all diagnoses. Such initiative should characterize the medical sequelae and economic burden and patient-reported outcomes to reflect the functional consequences, workforce participation, and sense of well-being. This information could serve as a foundation for AYA cancer research across the entire treatment trajectory, guiding interdisciplinary teams that combine pediatric and medical oncology expertise to fully support AYAs with cancer, enabling them to thrive for the full length of their restored lives after cancer.

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AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

Cost of Cancer in Adolescents and Young Adults in the United States: Results of the 2021 Report by Deloitte Access Economics, Commissioned by Teen Cancer America

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