

Age-Related Differences in Financial Toxicity and Unmet Resource Needs Among Adolescent and Young Adult Cancer Patients

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Financial toxicity may differ by age at diagnosis between adolescents and young adults (AYAs) with cancer. We surveyed 52 AYA cancer patients about unmet needs and financial toxicity using the Comprehensive Score for financial Toxicity (COST). We compared outcomes by age at diagnosis (15–25-year olds [$n=25$, 48%] vs. 26–39-year olds [$n=27$, 52%]). AYAs diagnosed ages 26–39 reported that cancer negatively affected their finances more than 15–25-year olds (77.8% vs. 37.5%, $p=0.0005$). Lower mean COST scores among those diagnosed ages 26–39 indicated greater financial toxicity compared to those 15–25 years (18.22 vs. 24.84, $p=0.02$). Financial burden appears to be greater for older AYAs with cancer.

Keywords: financial toxicity, unmet needs, age group

Introduction

FINANCIAL TOXICITY IS increasingly identified as a severe side effect of cancer, and patients diagnosed as adolescents and young adults (AYAs, between the ages of 15 and 39) are at high risk for this outcome.^{1–3} AYAs are often underinsured, which can lead to high out-of-pocket costs and cost-associated unmet care needs.^{4–6} AYAs may also be at an increased risk for financial issues due to their developmental stage, which generally includes transitioning to financial independence.^{7,8} Furthermore, AYAs may not have additional resources such as retirement funds or home equity which can ease the cost burden associated with treatment.^{9,10}

Differences in financial toxicity across the AYA age range could affect treatment adherence and outcomes. Older AYAs may have substantial financial responsibilities, including providing for family members, housing, insurance, and other bills, which can equate to increased financial need during cancer treatment.^{9,11,12} For younger AYAs, parents may provide some financial protection.⁸

In addition, the Patient Protection and Affordable Care Act's Dependent Coverage Mandate (DCM; which requires coverage for dependents up to age 26) provides many AYAs under the age of 26 years access to health insurance coverage through parental plans.¹³ Older AYAs (ages 26–39) may lack

access to insurance coverage if they live in one of the 14 states that have not expanded Medicaid or they do not qualify for subsidized insurance purchased through the Health Insurance Exchanges, potentially leaving them in the coverage gap.^{14,15} Younger AYAs may have less stable careers or may still be in school, which may limit their access to employer-sponsored insurance. Thus, a cancer diagnosis is likely financially disruptive for all AYA patients, but the degree to which financial issues differ by age remains generally unknown.¹⁶

Financial toxicity during cancer treatment is more complex than cost of treatment, unmet needs, or financial situation before diagnosis alone.¹⁷ The Comprehensive Score for financial Toxicity (COST) is a validated patient-reported tool that considers multiple aspects of cancer-related financial toxicity to compute an overall severity estimate.^{17,18} While several studies have investigated financial burden and unmet needs related to costs among AYAs,^{3,9,11,19} to our best knowledge, the COST tool has not been used to measure financial toxicity among AYA cancer patients.

In this study, we report on findings from a survey conducted with patients receiving navigation services through the Huntsman-Intermountain Adolescent and Young Adult (HIAYA) Cancer Care Program. The HIAYA Cancer Care Program provides patient navigation services for patients treated at Huntsman Cancer Institute (HCI), the only National Cancer

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Institute-designated comprehensive cancer center in Utah, and Intermountain Healthcare (IH), a system of 23 hospitals in Utah and Idaho that includes a children's hospital and community oncology providers. Together, HCI and IH see ~1,200 newly diagnosed AYA cancer patients per year, and the HIAYA Cancer Care Program sees ~200 patients annually. Patient navigation services are available to patients from diagnosis through survivorship.

Differences in financial toxicity between older and younger AYAs may change at age 26 when an AYA ages off parental coverage. Because of this insurance-related age restriction, we examined differences in financial toxicity among individuals diagnosed with cancer as AYAs by age group at diagnosis: 15–25 and 26–39 years. We report age-specific differences relating to AYA cancer's impact on health care access, work, and finances and use the COST tool to measure financial toxicity.

Materials and Methods

Eligible patients were diagnosed with cancer between 15 and 39 years old and met, at least once, with a HIAYA patient navigator. Between April 2017 and June 2018, we approached 103 patients; 53 participants were consented and enrolled; 52 completed the survey (50.1% participation rate).

Participants completed a 240-item survey, which included questions on the impact of cancer on health care access, work, finances, resources, and the 11-item COST measure.^{17,18} Survey items, outside of the COST measure, were developed based on literature review, existing surveys, and feedback from providers and the HIAYA patient and family advisory board. Rurality was calculated using residential zip code at time of survey through conversion to 2010 Rural-Urban Commuting Area (RUCA) Codes, with classification according to the Rural Health Research Center's categorization C.²⁰

Participants were divided into two groups by age at diagnosis (15–25 years vs. 26–39 years) due to the potential impact of the DCM on financial toxicity.^{13–15} Participants were asked to report (yes/no) whether they experienced resource concerns (e.g., housing costs), high medical cost concerns (e.g., prescription costs), and unmet needs (e.g., ability to work during treatment), which we analyzed by age at diagnosis using Fisher's exact tests. We summarized write-in responses for "other" categories in these domains.

We collapsed responses to impact of cancer questions from five-point Likert scales to dichotomous (positive to no impact vs. negative impact) responses and analyzed by age at diagnosis using Fisher's exact tests. Mean COST scores were calculated and compared by age at diagnosis using *t*-tests. As a secondary analysis, we examined COST scores by treatment status (about to start/in treatment vs. restarted/finished), tumor type (solid vs. leukemia/lymphoma), and physical disability within the past month (yes vs. no) using *t*-tests and ANOVA. Statistical significance was set at $p < 0.05$.

All study procedures were approved by the University of Utah Institutional Review Board. Informed consent, parental permission, and assents were obtained from all participants.

Results

The study sample ($n = 52$) consisted of 25 younger AYAs ages 15–25 years at diagnosis and 27 older AYAs diagnosed 26–39 years. Our sample was 46.2% male, 36.5% were

married, 48.1% reported a household income of less than \$40,000, all were insured (100%), and the majority lived in urban areas (88.5%).

Among younger AYAs (Table 1), 60.0% were male, 20.0% married, and 41.7% reported household incomes under \$40,000 a year. Many AYAs in this age group lived with (48.0%) and had health insurance coverage through (84.0%) their parents. Older AYAs had fewer male participants (33.3%), 51.9% were married, and 55.5% reported household incomes under \$40,000 a year. Most lived with their spouse/partner/children (63.0%), and all were insured through themselves or their spouses (100%).

When we examined the impact of cancer on health care access, work, and finances by age, there were few statistically significant differences (Table 2). Older AYAs reported a greater negative impact on their finances than younger AYAs (77.8% vs. 37.5%, $p = 0.005$).

For resource concerns, almost one-fourth of older AYAs reported problems with housing compared to younger AYAs (22.2% vs. 0%, $p = 0.02$). Similarly, older AYAs had greater worries about medical costs, including cost of appointments (37.0% vs. 12.0%) and prescriptions (29.6% vs. 8.0%) compared to the younger group. Other financial concerns were indicated by 44.4% of older AYAs compared to 12.0% of younger AYAs ($p = 0.005$). Write-in responses for other concerns focused on bills, living expenses, transportation and temporary lodging costs, and cost of treatment.

We calculated COST scores by age at diagnosis (Table 3). Scores range from 0 to 44, with lower scores indicating greater financial toxicity.^{17,18} Across each of the 11 COST items, older AYAs had lower scores than younger AYAs. In addition, total COST scores were lower for older AYAs (18.22 vs. 24.84, $p = 0.02$), indicating greater overall financial toxicity.

When we examined COST scores by treatment status, physical disability, and tumor type across age, no differences were observed for treatment. Older AYAs reporting a disability had a more severe COST score (mean = 11.00) compared to older AYAs without a disability (20.29) and younger AYAs with (26.50) and without (24.37) disability (overall p -value = 0.04). For tumor type, older AYAs with solid tumors reported the lowest mean COST score (14.73) followed by older AYAs with leukemia/lymphoma (22.58), younger AYAs with solid tumors (23.08), and younger AYAs with leukemia/lymphoma (26.46) (overall p -value = 0.03).

Discussion

In this study, AYAs diagnosed with cancer at older ages (26–39 years) consistently report greater burden and financial toxicity than AYAs diagnosed ages 15–25 years. Over 75% of older AYAs felt that cancer had a negative impact on their financial situation compared to less than 40% of younger AYAs. The cost of cancer treatment and associated expenses were also a greater concern among older AYAs compared to younger AYAs, with one-third of older AYAs concerned about high appointment and prescription drug costs compared to around 10% of younger AYAs. Older AYAs experienced significantly worse financial toxicity than younger AYAs as indicated by COST scores. Together, these results illustrate the substantial financial burden faced by many AYAs with cancer and demonstrate that older AYAs may be at particular risk for severe financial toxicity.

TABLE 1. DEMOGRAPHIC FACTORS BY AGE AT DIAGNOSIS (n=52)

	15–25-year olds (n=25)		26–39-year olds (n=27)	
	Median	Range	Median	Range
	20 n	15–25 %	29 n	26–39 %
Age at diagnosis				
Gender				
Female	10	40.0	18	66.7
Male	15	60.0	9	33.3
Marital status				
Married or living as married	5	20.0	14	51.9
Single, divorced, or separated	20	80.0	13	48.1
Current yearly income ^a				
<\$20,000	6	25.0	7	25.9
\$20,000–\$39,999	4	16.7	8	29.7
\$40,000–\$79,999	2	8.3	4	14.8
>\$80,000	4	16.7	4	14.8
Unknown/don't know	8	33.3	4	14.8
Living arrangement				
Parents	12	48.0	7	25.9
Spouse/partner/children	5	20.0	17	63.0
Other relatives	2	8.0	1	3.7
Friends/roommates	5	20.0	1	3.7
By myself	1	4.0	1	3.7
Cancer diagnosis				
Solid tumor	12	48.0	15	55.6
Leukemia	7	28.0	6	22.2
Lymphoma	6	24.0	6	22.2
How far in treatment				
About to start	1	4.0	1	3.7
In treatment	15	60.0	13	48.1
Restarted	2	8.0	3	11.1
Finished	7	28.0	10	37.1
Ethnicity				
Hispanic	2	8.0	2	7.4
Non-Hispanic	23	92.0	25	92.6
Race ^b				
White	23	95.8	23	85.2
Other	1	4.2	4	14.8
Insurance/other coverage ^c				
Public	2	8.0	4	18.5
Private	23	96.0	21	77.8
Christian Health Sharing Ministry	0	0	2	7.4
Insurance policy holder				
Self or spouse/partner	4	16.0	27	100
Parent	21	84.0	0	0
RUCA classification at study ^d				
Rural	3	12.0	3	11.1
Urban	22	88.0	24	88.9
Any physical disability ^e				
Yes	4	16.0	6	22.2
No	19	76.0	21	77.8

^aIncome included income from personal income, support from family, and financial assistance. Missing one response.

^bMissing one response.

^cChristian Health Sharing Ministries are organizations where health care costs are shared among members with similar religious beliefs.

^dUrban RUCA codes: 1.0, 1.1, 2.0, 2.1, 3.0, 4.1, 5.1, 7.1, 8.1, and 10.1; rural RUCA codes: 4.0, 4.2, 5.0, 5.2, 6.0, 6.1, 7.0, 7.2, 7.3, 7.4, 8.0, 8.2, 8.3, 8.4, 9.0, 9.1, 9.2, 10.0, 10.2, 10.3, 10.4, 10.5, and 10.6.

^eReported issues with a disability in the past month. Missing two responses.
RUCA, Rural-Urban Commuting Area.

TABLE 2. IMPACT OF CANCER, UNMET NEEDS, AND RESOURCE CONCERNS RELATED TO WORK, INSURANCE, AND FINANCES BY AGE AT DIAGNOSIS

	15–25-year olds (n=25)		26–39-year olds (n=27)	
	n	%	n	%
Negative impact of cancer on				
Financial situation ^a	9	37.5	21	77.8
Plans for work	10	41.7	12	52.2
Unmet needs in the past month				
Health care access/insurance				
Inadequate insurance ^b	4	16.7	5	18.5
Getting home health care	0	0	2	7.4
Transportation costs and barriers ^b	8	16.0	5	18.4
Far distance to appointments	7	28.0	6	22.2
Needing lodging for appointments	1	4.0	2	7.4
Employment				
Ability to work during treatment	10	40.0	14	51.9
Going back to work after treatment	6	24.0	10	37.0
Finding job during treatment	3	12.0	3	11.1
Caregiver’s employment difficulties	1	4.0	6	22.2
Communicating with employer	2	8.3	2	7.4
Other employment issues	1	4.0	3	11.1
Resource concerns				
Housing ^a	0	0	6	22.2
Food and groceries	2	8.0	7	25.9
Clothing	0	0	2	7.4
Utilities/bills	3	12.0	8	29.6
Other household concerns ^b	0	0	2	7.7
Concerns about high costs of				
Medical appointments	3	12.0	10	37.0
Prescriptions	2	8.0	8	29.6
Home health care	0	0	3	11.1
Medical equipment	0	0	4	14.8
Child or elder care during appointments/treatment	0	0	2	7.4
Other financial concerns ^a	3	12.0	12	44.4

^a $p \leq 0.05$ for Fisher’s exact test.

^bMissing responses.

TABLE 3. COMPREHENSIVE SCORE FOR FINANCIAL TOXICITY MEASURE BY AGE AT DIAGNOSIS^a

	15–25-year olds (n=25)		26–39-year olds (n=27)	
	Mean	Standard deviation	Mean	Standard deviation
I know that I have enough in savings, retirement, or assets to cover the cost of my treatment	2.04	1.68	1.41	1.53
My out-of-pocket medical expenses are more than I thought they would be	2.83	1.05	2.19	1.52
I worry about the financial problems I will have in the future as a result of my illness or treatment	2.13	1.45	1.41	1.28
I feel I have no choice about the amount of money I spend on care	2.00	1.14	1.70	1.35
I am frustrated that I cannot work or contribute as much as I usually do	1.64	1.47	1.12	1.14
I am satisfied with my current financial situation	1.96	1.49	1.33	1.39
I am able to meet my monthly expenses	2.75	1.11	2.07	1.30
I feel financially stressed	2.54	1.35	1.67	1.27
I am concerned about keeping my job and income, including working at home	3.08	1.21	2.37	1.36
My cancer or treatment has reduced my satisfaction with my present financial situation	2.63	1.44	1.59	1.45
I feel in control of my financial situation	2.21	1.38	1.41	1.45
Total COST score ^b	24.84	10.98	18.22	10.31

^aSummed scores range from 0 to 44, with lower scores indicating greater financial toxicity.^{17,18}

^b $p=0.02$.

COST, COmprehensive Score for financial Toxicity.

The limited literature available on financial toxicity in AYA cancer patients suggests that their life stage may place them at a higher financial risk during cancer because they have financial responsibilities that older and younger cancer patients do not (e.g., paying back student loans, starting new careers, establishing families, and oncofertility costs).^{16,21} Older AYAs with cancer may be solely responsible for their health care and related costs, whereas younger individuals often receive financial support from their parents.^{8,11} Moreover, older AYAs in our sample tend to hold their own insurance policy, possibly increasing older AYAs insurance cost burden. Our subanalysis suggests that additional factors, such as physical disability and tumor type, may increase financial toxicity particularly among older AYAs.

We found that basic resource concerns such as housing, food, and utilities/bills were common for older AYAs. Our results parallel an analysis of AYA Samfund recipients, a grant that provides financial assistance to AYA cancer survivors, that identified higher monthly expenses and total liabilities among AYA survivors in their thirties, suggesting that financial toxicity may be more acute in this group.⁹ While we used a wider age range than the Samfund analysis to indicate the potential loss of DCM coverage, our findings remain consistent regarding higher needs among older AYAs.

The COST measure was designed to include themes representative of financial toxicity across many topics, including savings, out-of-pocket costs, impact on financial future, current financial situation, and job concerns.¹⁷ Mean COST scores for cancer patients identified as high risk for financial toxicity in earlier studies include African Americans (18.92) and Hispanics (18.46), which closely align with our findings for older AYAs (18.22).¹⁸ However, younger AYAs in our sample (24.84) align with the mean score for Whites (23.90).¹⁸

These findings have important implications for improving the health outcomes of AYAs with cancer. High levels of financial toxicity have been associated with poor treatment adherence, which may be a barrier to clinical trial participation.²² Despite several national efforts to increase their participation, AYAs continue to have the lowest clinical trial participation of all age groups in the United States.^{23,24} Survival rates for AYA cancer have not improved as they have for children and older adults, suggesting that the substantial financial burden experienced by AYAs may be an important factor in disparities in survival.¹⁰ Our subanalysis suggests that additional factors, such as physical disability and tumor type, may increase financial toxicity not only overall but specifically among older AYAs.

Certain limitations exist for this study. We were limited in our sample size and participant racial/ethnic diversity, which may limit generalizability. However, our findings parallel earlier findings that older AYAs suffer more financially.^{9,11} Furthermore, we had more older AYAs who were female, which could have biased our findings as female survivors generally express higher financial toxicity.²⁵ In addition, we recruited participants who had interacted with an AYA patient navigator. Patients seeing a navigator may be referred by their provider for a variety of reasons, including resource concerns. However, the HIAYA Cancer Care Program is a supportive care service offered to all AYA cancer patients with no particular focus on finances or insurance; as such, we believe our findings are likely generalizable to AYA cancer patients who have not met with a navigator.

This study suggests that AYAs diagnosed ages 26 and over may feel the effects of cancer-related financial toxicity more than younger AYAs and may have different or additional unmet needs than younger AYAs. This information should assist in the creation of financial action plans specifically tailored to the needs of older AYAs. As older AYAs may be at an increased risk for financial toxicity, social workers and patient navigators working with AYAs may want to provide additional support for this age group while ensuring that all AYAs have age-appropriate guidance on financial needs. Early identification of patients at risk for financial toxicity and appropriate interventions may help ease cancer cost burden and prevent or lessen the development of unmet needs.

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Disclaimer

The content of this article is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

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References

- Zafar SY, Abernethy AP. Financial toxicity, part I: a new name for a growing problem. *Oncology*. 2013;27(2):80–149.
- Watson S, Landwehr MS. Financial toxicity and the young adult cancer survivor. *AJMC Evid Based Oncol*. 2015; 21(14):SP482-3.
- Muffly LS, Tardif C, de Souza J. Financial toxicity in children, adolescent, and young adult cancer patients and their families: a large national registry analysis from the family research foundation. *J Clin Oncol*. 2016;34(15_suppl): 6615.
- Kaul S, Avila JC, Mehta HB, et al. Cost-related medication nonadherence among adolescent and young adult cancer survivors. *Cancer*. 2017;123(14):2726–34.
- Kaul S, Fluchel M, Spraker-Perlman H, et al. Health care experiences of long-term survivors of adolescent and young adult cancer. *Support Care Cancer*. 2016;24(9):3967–77.
- Kirchhoff AC, Lyles CR, Fluchel M, et al. Limitations in health care access and utilization among long-term survivors of adolescent and young adult cancer. *Cancer*. 2012; 118(23):5964–72.
- Arnett JJ. Conceptions of the transition to adulthood: perspectives from adolescence through midlife. *J Adult Dev*. 2001;8(2):133–43.
- Hartnett CS, Furstenberg FF, Birditt KS, Fingerman KL. Parental support during young adulthood: why does

- assistance decline with age? *J Fam Issues*. 2012;34(7):978–1007.
9. Landwehr MS, Watson SE, Macpherson CF, et al. The cost of cancer: a retrospective analysis of the financial impact of cancer on young adults. *Cancer Med*. 2016;5(5):863–70.
 10. Isenalumhe LL, Fridgen O, Beaupin LK, et al. Disparities in adolescents and young adults with cancer. *Cancer Control*. 2016;23(4):424–33.
 11. Keegan THM, Lichtensztajn DY, Kato I, et al. Unmet adolescent and young adult cancer survivors information and service needs: a population-based cancer registry study. *J Cancer Surviv*. 2012;6(3):239–50.
 12. Kent EE, Parry C, Montoya MJ, et al. “You’re too young for this”: adolescent and young adults’ perspectives on cancer survivorship. *J Psychosoc Oncol*. 2012;30(2):260–79.
 13. Patient Protection and Affordable Care Act. 124 STAT 132: Authenticated U.S. Government Information GPO, 2010. Retrieved from: <http://congress.gov/111/plaws/pub1148/PLAWS-111pub148.pdf>. Accessed August 27, 2019.
 14. Parsons HM, Schmidt S, Tenner LL, et al. Early impact of the Affordable Care Act on insurance among young adults with cancer: analysis of the dependent insurance provision. *Cancer*. 2016;122(11):1766–73.
 15. Alvarez EM, Keegan THM, Johnston EE, et al. The Patient Protection and Affordable Care Act dependent coverage expansion: disparities in impact among young adult oncology patients. *Cancer*. 2017;124(1):110–7.
 16. Warner EL, Kent EE, Trevino KM, et al. Social well-being among adolescents and young adults with cancer: a systematic review. *Cancer*. 2016;122(7):1029–37.
 17. De Souza JA, Yap BJ, Hlubocky FJ, et al. The development of a financial toxicity patient-reported outcome in cancer: the COST measure. *Cancer*. 2014;120(20):3245–53.
 18. De Souza J, Yap BJ, Wroblewski K, et al. Measuring financial toxicity as a clinically relevant patient-reported outcome: the validation of the COmprehensive Score for Financial Toxicity (COST). *Cancer*. 2017;123(3):476–84.
 19. Ketterl TG, Syrjala KL, Casillas J, et al. Lasting effects of cancer and its treatment on employment and finances in adolescent and young adult cancer survivors. *Cancer*. 2019;0:1–10.
 20. Rural-Urban Commuting Area Codes (RUCAs): using RUCA data. Rural Health Research Center, 2012. Retrieved from: <http://depts.washington.edu/uwruca/ruca-uses.php>. Accessed July 25, 2019.
 21. Printz C. Illinois becomes fifth state to guarantee coverage for oncofertility treatments. *Cancer*. 2019;125(6):833.
 22. Winkfield KM, Phillips JK, Joffe S, et al. Addressing financial barriers to patient participation in clinical trials: ASCO policy statement. *J Clin Oncol*. 2018;36(33):3331–9.
 23. Tran G, Zafar SY. Financial toxicity and implications for cancer care in the era of molecular and immune therapies. *Ann Transl Med*. 2018;6(9):166–76.
 24. Bleyer A, Tai E, Siegel S. Roles of clinical trials in survival progress of American adolescents and young adults with cancer- and lack thereof. *Pediatr Blood Cancer*. 2018;65(8):e27074–92.
 25. Knight TG, Deal AM, Dusetzina SB, et al. Financial toxicity in adults with cancer: adverse outcomes and non-compliance. *J Oncol Pract*. 2018;14(11):e665–73.

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