

# FINANCIAL CHALLENGES FACED BY AYAs WITH CANCER

**Susan Parsons, MD, MRP**

**Medical Director, Reid R. Sacco AYA Cancer Program  
Tufts Medical Center  
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## OVERVIEW

- Unique financial issues for AYAs
- Reciprocal impact of care on finances & finances on care
- Challenges in assessing financial toxicity
- Future directions

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## AYA: PERIOD OF FINANCIAL UNCERTAINTY

- **Developmentally complex period**
- **Vocational & educational attainment**
- **Transition from home to independent living**
- **Transition from parents' health insurance coverage to other sources**
  - Employer-provided insurance
  - Health exchange
  - Public insurance

## CURRENT AYA POPULATION MAY BE EVEN MORE VULNERABLE

- **Great Recession 2008**
  - Loss of existing savings
  - Less wealth
  - Less home ownership
- **Dramatic increase in cost of education**
  - Debt burden: \$250 Billion in 2009; \$1.2 Trillion in 2018
- **Lower rates of marriage & at older age**
  - Lower household income

## AYA: HISTORICALLY LARGEST PROPORTION OF UNINSURED OR UNDERINSURED

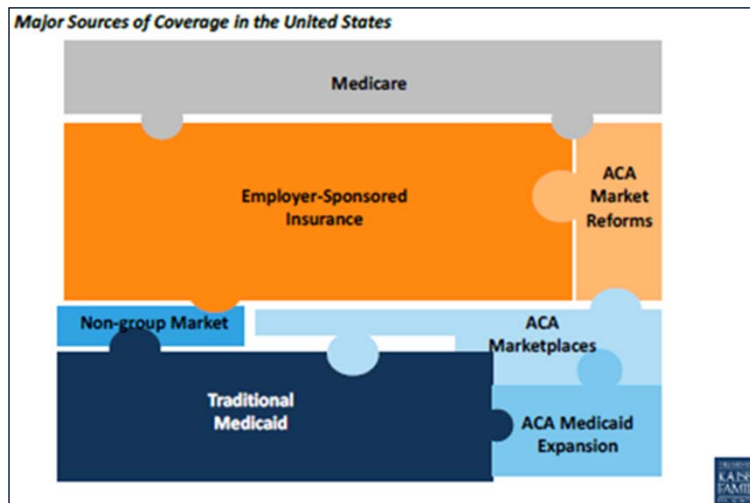
- **Gaps due to access to & cost of health insurance**
  - Most private insurance available through medium-sized & large employers
  - Pre-existing condition
    - Denied coverage
    - Individually underwritten at higher cost
  - Loss of coverage when age out of family-based coverage
  - “Job lock” for fear of losing coverage
  - Insurance “churn” threatens continuity of care

## HEALTH INSURANCE QUAGMIRE

## SOURCES OF HEALTH INSURANCE BY DEVELOPMENT STAGE

Adolescence	Emerging Adulthood	Older Young Adulthood
Parental coverage Private Public	Dependent Coverage Expansion ( <i>private insurance only</i> )	--
CHIP/Medicaid Spend Down	Medicaid Spend Down Limited earnings	Medicaid Spend Down Limited earnings
	Health Exchange	Health Exchange
	Disability	Disability

## THE ACA FILLS IN GAPS IN A PIECEMEAL INSURANCE SYSTEM



Foutz J, Squires E, Garfield R, et al. *The uninsured: a primer*, The Henry J. Family Foundation. 2017. <https://www.kff.org/uninsured/report/the-uninsured-a-primer-key-facts-about-health-insurance-and-the-uninsured-under-the-affordable-care-act/2017>

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## THREATS TO ACA: IMPACT ON AYA

- Debates about elimination of pre-existing condition
- Income restrictions to Medicaid eligibility
- Phase out of government subsidies
- Limitations to Medicaid expansion
- Proliferation of high-deductible health plans or other short-term policies

## CASE 1

### **27 year old, diagnosed in late adolescence with Hodgkin lymphoma.**

- Treated with multi-agent chemotherapy and chest irradiation.
- Within 5 years of completing treatment, noted to have reduced cardiac functioning and begun on afterload reduction and beta blockers.
- Receiving care from cardio-oncologist and AYA Program.

*“I consider myself to be a pretty healthy guy. I can keep up with all of my friends when I play rugby with them. That’s why I bought the high deductible plan.”*

## INSURANCE LITERACY

*“I didn’t understand why I got the bill for the echo. I’d called the insurance company and they told me it would be covered...”*

### Answer

- The testing would be covered *after* the annual deductible was paid.

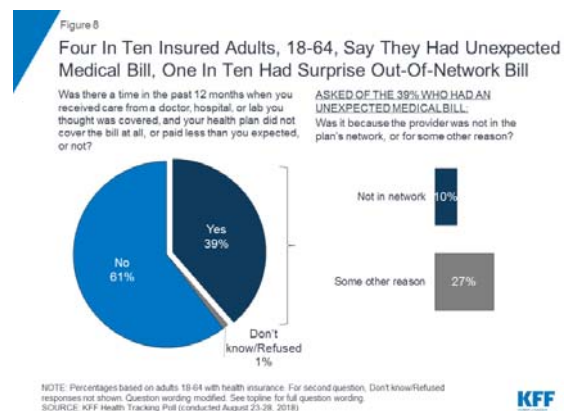
### Solution

- Selected different product during the next open enrollment period and contributed regularly to a health saving account to cover other expenses.

## FINANCIAL CONSEQUENCES OF CANCER: TYPES OF COSTS

### • Medical Cost

- Monthly insurance premiums
- Annual deductibles
- Co-pays and co-insurance
- Uncovered or partially covered services
  - Out of network restrictions
  - “Surprise billing”
    - 2/3rds insured adults worried about being able to afford bills
  - Denied claims—triggering peer-to-peer reviews +/- escalation



## ADDITIONAL COSTS ASSOCIATED WITH CARE SEEKING

- **Non-medical Cost**

- Lost productivity due to premature death (mortality cost)
- Time lost from work due to short-term & long-term morbidity (morbidity cost)
  - Absenteeism (lost wages, especially for hourly workers) or consumption of benefits
  - Presenteeism
- Time spent receiving cancer care
- Intangibles-loss in quality of participation within and outside home
- Myriad out of pocket expenses
  - Parking/Transportation
  - Meals
  - Child care

## CASE 2

### **30 year old with thyroid cancer, secondary to cranio-spinal irradiation for Non-Hodgkin lymphoma, diagnosed at age 6.**

- Began missing appointments to have thyroid labs checked and stopped seeing therapist due to the cost of co-pays.
- When her family relocated out of the area, she tried to get her own apartment. However, when her prospective landlord pulled her credit report, he discovered that her account was in collections for unpaid bills over the prior 8 years.

*“How could I be in collections? I always had insurance through my parents. I just ignored the bills, because I knew I was insured.”*

## BEING INSURED DOES NOT MEAN NO BILLS: *EVEN THE INSURED ARE VULNERABLE*

- **Solution**

- AYA Program negotiated with collection agency which agreed to accept final payment for half of the outstanding balance. Philanthropic funds zeroed out the balance.
- AYA Program assisted patient in applying for disability insurance, which would allow her to continue to work 20 hours per week in her job and retain her apartment.

## ADJUSTED PER PERSON ANNUAL MEDICAL EXPENDITURES AMONG AYA CANCER SURVIVORS & ADULTS WITHOUT A HISTORY OF CANCER, 2008-11

SOURCE OF PAYMENT	Cancer survivors		Adults without cancer	
	Adjusted expenditures	95% CI	Adjusted expenditures	95% CI
All <sup>***</sup>	\$7,417	(6,133, 8,700)	\$4,247	(4,142, 4,352)
Out of pocket <sup>**</sup>	765	(684, 846)	686	(670, 701)
Private insurance <sup>****</sup>	3,083	(2,312, 3,854)	1,825	(1,758, 1,892)
Medicare <sup>*</sup>	1,246	(898, 1,594)	948	(901, 996)
Medicaid <sup>*</sup>	541	(361, 721)	380	(342, 418)
Other <sup>****</sup>	876	(578, 1,174)	411	(387, 435)
<b>SERVICE TYPE</b>				
Ambulatory care <sup>****</sup>	2,409	(1,851, 2,968)	1,376	(1,335, 1,417)
Inpatient care <sup>**</sup>	1,605	(1,115, 2,096)	1,169	(1,116, 1,221)
Rx <sup>****</sup>	1,466	(1,241, 1,691)	1,034	(970, 1,099)
Other <sup>**</sup>	820	(694, 946)	686	(658, 714)

**SOURCE** Authors' analysis of data from the 2008-11 Medical Expenditure Panel Surveys (MEPS). **NOTES** Adolescent and young adult cancer survivors are those whose first diagnosis of cancer occurred at ages 15-39. Adults with no history of cancer (except for nonmelanoma skin cancer) are ages eighteen and older. All monetary amounts were converted to 2011 dollars using the Personal Health Care Expenditure Price Index. Regressions controlled for age, sex, race or ethnicity, number of MEPS priority conditions, and census region using a two-part model. The sums of the components do not equal the totals because of nonlinearities. CI is confidence interval. <sup>\*</sup>Office-based provider visits and outpatient visits. <sup>†</sup>Emergency department visits, home health visits, dental visits, vision expenses, and other medical expenditures. <sup>\*</sup>p < 0.10 <sup>\*\*</sup>p < 0.05 <sup>\*\*\*\*</sup>p < 0.001

Adapted from: Guy G, Yabroff KR, Ekwueme, DU, et al. Estimating the health and economic burden of cancer among those diagnosed as adolescents and young adults. Health Affairs 2014; 33(6):1024-1031

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## AYA HEALTH OUTCOMES & PATIENT EXPERIENCE (HOPE) STUDY (N=524, Ages 15-39)

- 2/3 reported negative impact on finances
- 11% lost insurance coverage in prior year
  - Loss of insurance associated with lower health-related quality-of-life (HRQL) & worse fatigue
- Negative impact on employment & education
- Disruption in social roles

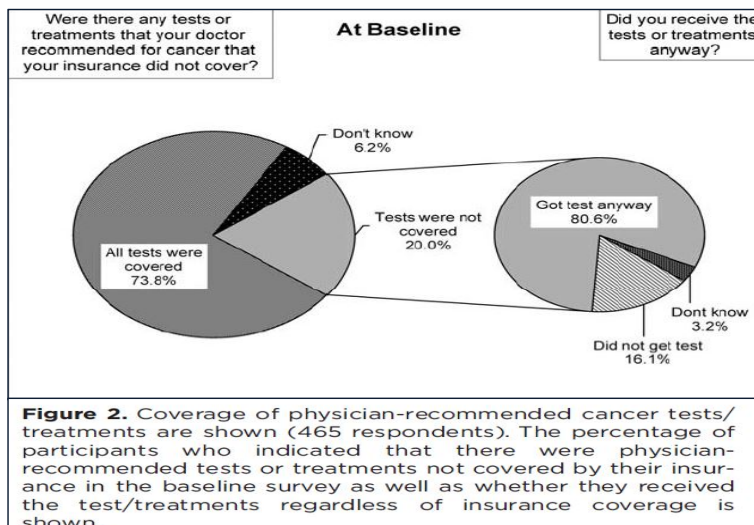
Wilder Smith A, Keegan T, Hamilton A, et al. Understanding the care and outcomes in adolescents and young adults with cancer: A review of the AYA HOPE study. *Pediatric Blood* 2019;66:e27486

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## CARE SEEKING BY INSURANCE COVERAGE



Parsons HM, Schmidt S, Harlan LC et al. Young and uninsured: insurance patterns of recently diagnosed adolescent and young adult cancer survivors in the AYA HOPE study. *Cancer*. 2014;120:2352-60

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## AYA-AGED SURVIVORS OF CHILDHOOD CANCER REPORT SIMILAR FINDINGS

- **2008-2011 Medical Expenditure Panel Survey (MEPS)**
  - Survivors more likely to report fair to poor health
  - Less likely to be employed
  - Higher medical expenditures
  - More likely to be disabled
  - More likely to have functional limitations
- **St. Jude Lifetime Cohort**
  - Financial hardship (14% severe; 37% moderate)
  - Highlighted impact of lower educational attainment, lower household income, and chronic health conditions on severity of financial hardship

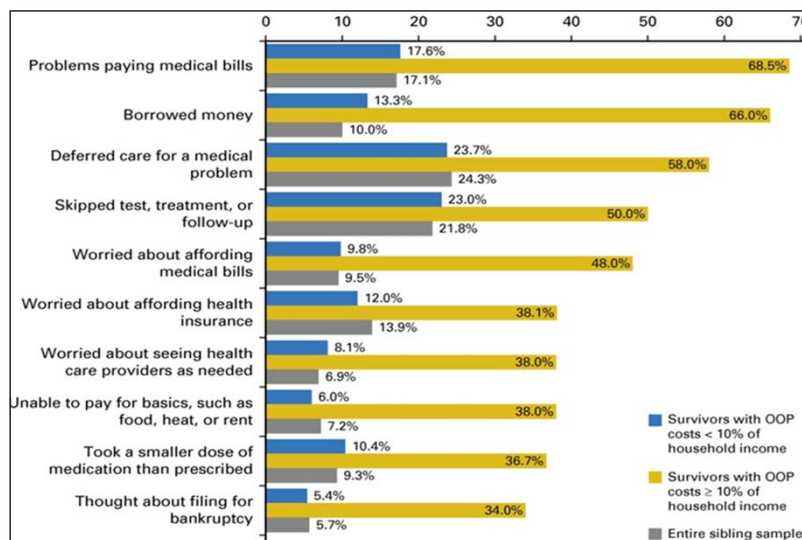
Guy et al., 2014; Brinkman et al., 2018

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## FINANCIAL BURDEN AMONG SURVIVORS OF CHILDHOOD CANCER & SIBLINGS



Nipp RD, Kirchoff AC, Fair D, et al. Financial burden in survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. *J Clin Oncol.* 2017;35(30):3474-3481

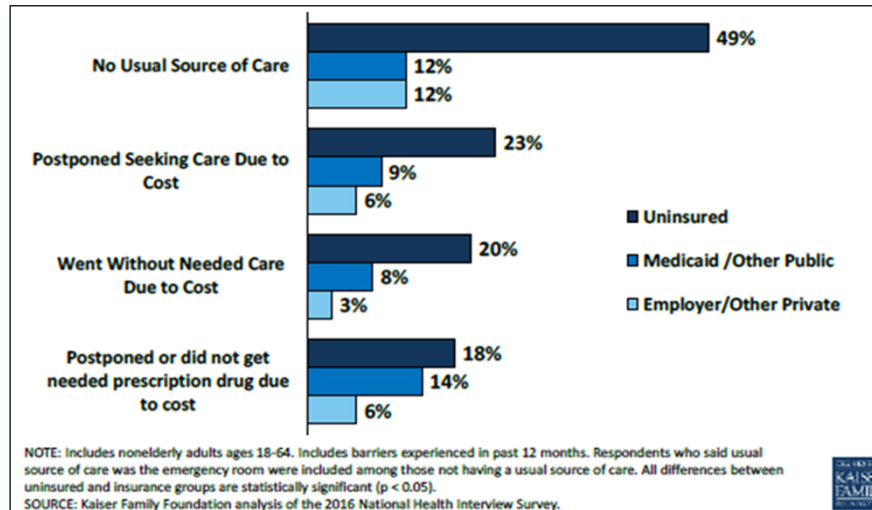
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## BARRIERS TO HEALTH CARE AMONG NONELDERLY ADULTS BY INSURANCE STATUS, 2016



Foutz J, Squires E, Garfield R, et al. *The uninsured: a primer*, The Henry J. Family Foundation. 2017. <https://www.kff.org/uninsured/report/the-uninsured-a-primer-key-facts-about-health-insurance-and-the-uninsured-under-the-affordable-care-act/2017>

## CHALLENGES IN ADDRESSING FINANCIAL TOXICITY

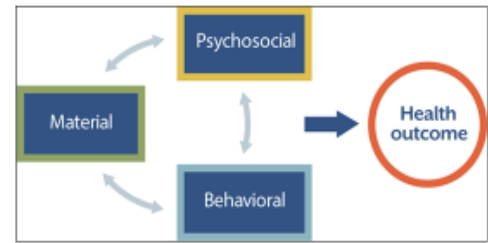
- Currently not integrated into care
- Is it time for another vital sign?

*“My illness has been a financial hardship for my family and me.”*

## INITIAL CONCEPTUAL FRAMEWORK

(SALSMAN, WAKE FOREST SCHOOL OF MEDICINE)

- **MATERIAL- Financial – Resources & Assets**
  - E.g., enough for basics, no debt
- **MATERIAL- Financial – Expenses & “Hits”**
  - E.g., no insurance, lost income, job loss
- **PSYCHOSOCIAL- Financial Distress**
  - E.g., emotional distress, worry about paying bills, lack of control
- **BEHAVIORAL- Behavioral & Adaptive Strategies**
  - E.g., do not adhere to medication or treatment, borrow money, refinance home, use credit card more
- **HEALTH OUTCOME**
  - E.g., survival, symptoms, quality of life



Altice et al. (2017) Financial hardships experienced by cancer survivors: a systematic review. *J Natl Cancer Inst*, 109(2).

## RESULTS- EMERGENT THEMES

1. Challenges paying for costs associated with cancer/treatment.
2. Costs of cancer beyond medical treatment.
3. Financial burden has long-lasting effects.
4. Status of health insurance coverage shapes awareness of financial burden related to cancer/treatment.
5. Navigating financial components of the healthcare system is overwhelming.
6. Effective patient-provider communication about financial issues is lacking.
7. Perceived financial burden negatively affects psychological health.
8. Patients employ various psychological/behavioral strategies for coping with financial burden.
9. Patients seek/receive funds and support to manage cancer costs.
10. Patient health/medical decisions and behaviors are negatively affected by financial concerns.

# ADVICE FROM A PATIENT ADVOCATE TO ADDRESS TRIAL PARTICIPATION & POTENTIAL FINANCIAL TOXICITY

- Patient or their caregivers might need assistance to anticipate & manage short- or long-term financial, school or workplace distress upon enrollment.
- Do not assume there is not moderate to severe cancer-related distress.
- Do not assume those in moderate to severe distress cannot participate.
- Do all you can to make it possible for them to participate.
- Be prepared with referral resources for patients & caregivers.

Special thanks to Hildy Dillon, SWOG Lymphoma Committee Patient Advocate

## ANTICIPATE/MANAGE CANCER COSTS (SWOG S1826)

**FRANKLY SPEAKING ABOUT CANCER** Tips for Managing and Budgeting Your Cancer Costs

When you or a loved one has cancer, you are focused on the disease, treatment, and doctors. Many people forget to ask questions that can help them manage the costs associated with facing cancer – important questions like “How much will all of this cost?” and “How can I manage these costs?” The first half of this booklet can help you understand the financial aspects of a cancer diagnosis. The second half can help you budget for your total estimated cancer costs. We hope that this will help you learn about your options, ask questions, and take control of your treatment and costs.

CANCER SUPPORT COMMUNITY

### Doctor's Appointments

What is your co-pay or co-insurance for each doctor visit? How often will you see your doctors?

DO THE MATH

Number of appointments per month	co-pay/ co-insurance cost	number of months left in your plan year	ESTIMATED EXPENSE
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
x		x	- \$

### Scans

What is your co-pay or co-insurance for a scan? How often will you need one?

DO THE MATH

Number of scans expected this year	co-pay/co-insurance cost	ESTIMATED EXPENSE
<input type="text"/>	<input type="text"/>	<input type="text"/>
x		- \$

### Radiation Therapy

Will you need radiation therapy? What is your co-pay or co-insurance for each appointment? How many appointments will you need?

DO THE MATH

Number of radiation appointments in this plan year	co-pay/co-insurance cost	ESTIMATED EXPENSE
<input type="text"/>	<input type="text"/>	<input type="text"/>
x		- \$

**TIP** Ask what type of radiation you are receiving and if there is another type that is as effective but less expensive.

### Chemotherapy

Will you need chemotherapy? Will you receive one drug or a combination of drugs? What will your chemotherapy plus any drugs your team expects to use to treat or reduce their side effects cost?

DO THE MATH

Number of rounds of chemotherapy in this plan year	cost of chemotherapy and expected prescription drug co-pay per round	ESTIMATED EXPENSE
<input type="text"/>	<input type="text"/>	<input type="text"/>
x		- \$

**TIP** Are there chemotherapy options that are as effective but may be less expensive? Is there a patient assistance program?

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# ANTICIPATE/MANAGE CANCER COSTS (SWOG)

### OTHER HOUSEHOLD COSTS

If you keep a household budget, you know how quickly expenses can add up. Cancer will affect your budget in both little and big ways. If you are the head cook in your house, you will have less time to cook or look for bargains. You may end up eating out or ordering in. You may need to call a taxi instead of drive. You may need to hire someone to come in and clean your house. All of this can add up quickly.

**THINK ABOUT ▼**

	ESTIMATED EXPENSES
How much more will you spend than usual on transportation/travel costs?	\$
Do you have family that requires care that you will not be able to provide during your cancer treatment? Will you have to pay someone to perform this care? If so, how much will that cost?	\$
Will you need a home health aide while recovering? What will it cost?	\$
Will you have additional childcare costs? How much?	\$
Will your housing/home situation change because of your cancer treatment?	\$
Will you need temporary housing during treatment? What will it cost?	\$
Do you need to pay an attorney to help you develop Advance Directives, Living Wills, or instructions related to your care and quality of life choices? How much will that cost?	\$
What other additional household expenses might you pay this year due to your cancer treatment? How much will that cost?	\$

**ADD TOGETHER ALL YOUR ESTIMATED HOUSEHOLD EXPENSES ▼**  
(add together all the amounts in purple boxes).

**THIS IS YOUR TOTAL ESTIMATED HOUSEHOLD COST**

\$

**TIP** There are resources to help reduce some of these costs. Have a family member or friend set up a website, like MyLifeLine.org, that lets people who want to help you know what you need.

### CHANGES TO YOUR INCOME

If you are employed, being diagnosed with and treated for cancer is likely to affect your ability to work. This, in turn, can affect your income. You should know the answers to these questions:

What are your options for working during treatment? If you need to take an extended absence from work, what are your options for returning to work? Can you work part-time?

**THINK ABOUT ▼**

	ESTIMATED INCOME CHANGE
If you think you will earn less than usual this year due to occasional or extended absences from work, try to estimate how much less you will earn.	\$
Have you asked your employer about options (for example, possible COBRA coverage) in case you are not able to work and continue with your current insurance? If you will have to start paying for your own insurance or COBRA coverage, how much will that cost this year?	\$
Do you have short-term or long-term disability insurance that might help with costs and financial planning? If so, try to estimate how much they will pay this year.	-\$

**CALCULATE YOUR ESTIMATED CHANGE IN INCOME ▼**  
Add together how much less you will earn and how much you will pay for insurance that your employer used to pay (BROWN BOXES) and subtract any disability payments (BLUE BOX).

**THIS IS THE TOTAL AMOUNT YOU ESTIMATE CANCER TREATMENT WILL DECREASE YOUR INCOME THIS YEAR**

\$

NOTES

## SUMMARY

- AYAs with cancer face financial hardship during & after cancer.
- Financial burden may affect care seeking behaviors in ways not obvious to care team.
- Having health insurance is not complete protection.
- Financial toxicity may interfere with clinical trials participation & follow-up care.
- Financial navigation & counseling are needed to guide product selection & financial management.

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