

ACA Provisions Affecting Adolescent and Young Adult Populations

**Impact of the Affordable Care Act on Cancer Prevention
and Cancer Care: A Virtual Workshop
March 1, 2021**

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Adolescents and young adults with cancer

- AYAs – diagnosed with cancer ages 15 to 39 years of age – are described as “lost in the gap” between pediatric and adult care.
- AYAs tend to have fewer resources to manage medical costs, and less experienced with insurance concepts and managing medical costs.
- Young adults have historically be uninsured more often than older adults.

For Young Adults, “Cancer Recovery” Is A Loaded Term

JUNE 21, 2019 / NFCR WRITER DAVID PERRY / BLOG



<https://www.nfcr.org/blog/for-young-adults-cancer-recovery-is-a-loaded-term/>

Patient Protection and Affordable Care Act

- The 2010 ACA established provisions intended to increase access to affordable health insurance for populations with pre-existing conditions
- Specific provisions of the ACA that benefit young cancer patients include:
 - ✓ Pre-existing conditions coverage
 - ✓ Dependent coverage expansion to age 26
 - ✓ Medicaid expansion
 - ✓ No lifetime limits



ACA's effect on insurance coverage for AYAs with cancer

- ACA's dependent coverage has increased private insurance coverage for AYAs up to age 26 years
 - Disparities in access by race/ethnicity and for AYAs living in less socioeconomically stable communities
 - Male AYAs have had greater insurance gains than female AYAs
- Medicaid expansion led to immediate improvements in insurance coverage among AYAs with cancer
- AYAs over age 26 have not made the same coverage gains as those eligible for dependent coverage

CCSS insurance experiences prior to ACA

Insured survivors

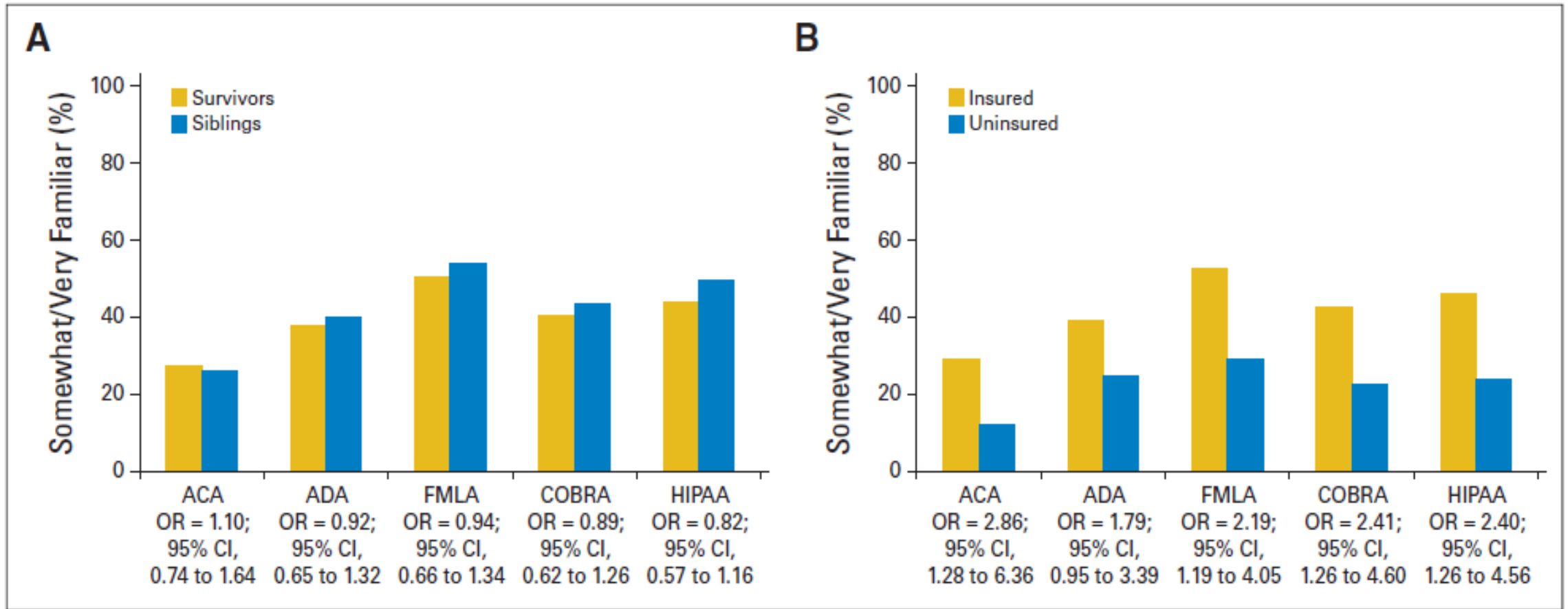
- “We have a huge deductible because we’re paying, you know, like a thousand a month....But that’s all we could do, we both have pre-existing conditions.”
- “If I wouldn't have had that option [to stay on my parents' insurance]...I wouldn't be able to go to school because I'd [have] to work full-time to get insurance...and we would be in a lot of debt.”

Uninsured survivors

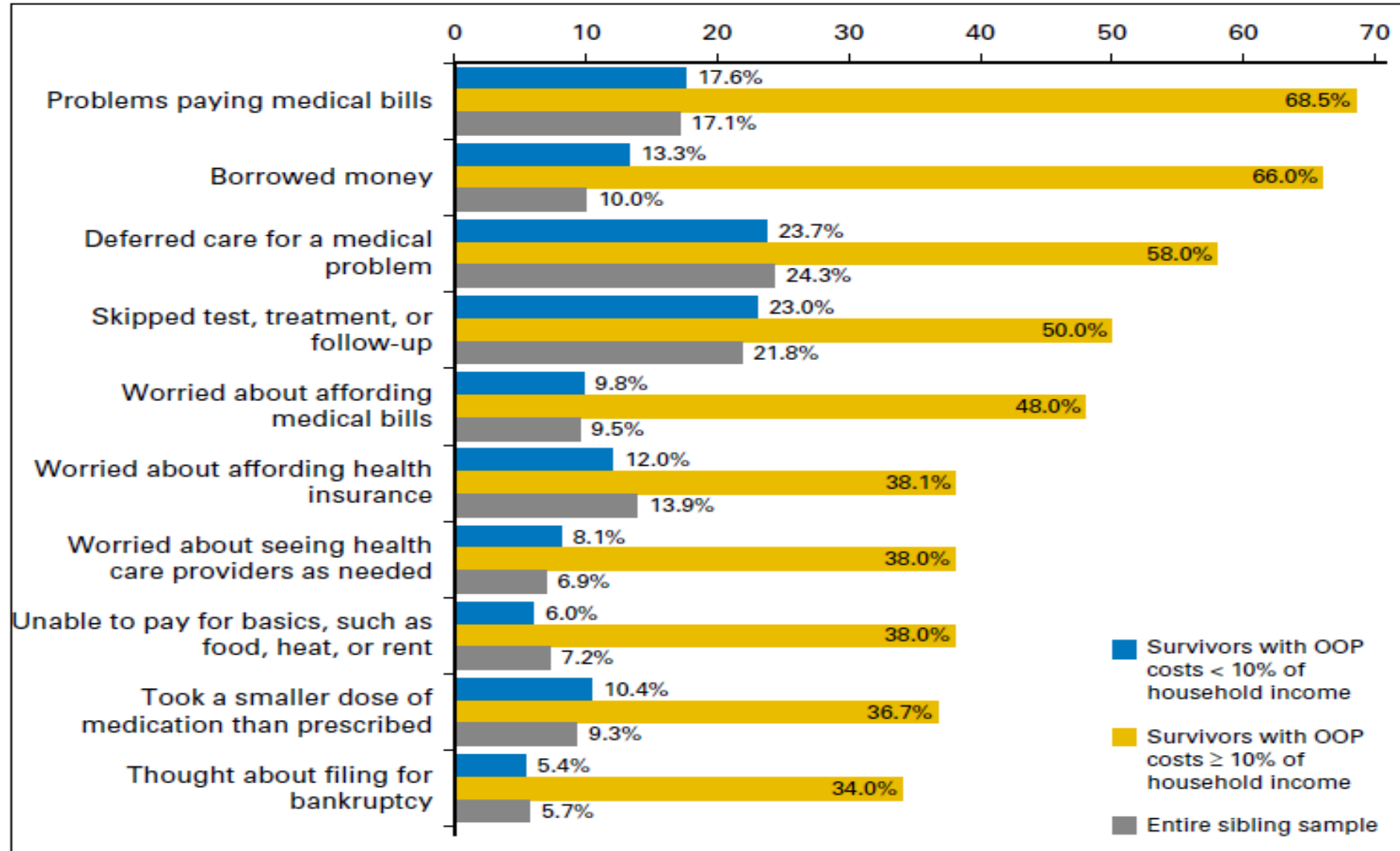
- “Yeah it does concern me that, if something happens....Nobody’s going to give me insurance. That’s a pre-existing condition and a million dollars worth of bills.”

CONCERNS	HOPES
Cost of Coverage	Cost of Coverage
Insurance Coverage	Insurance Coverage
Access to Care	Access to Care
Quality of Care	Quality of Care
Government Involvement	Government Involvement
Impact on Employer/ESI	---

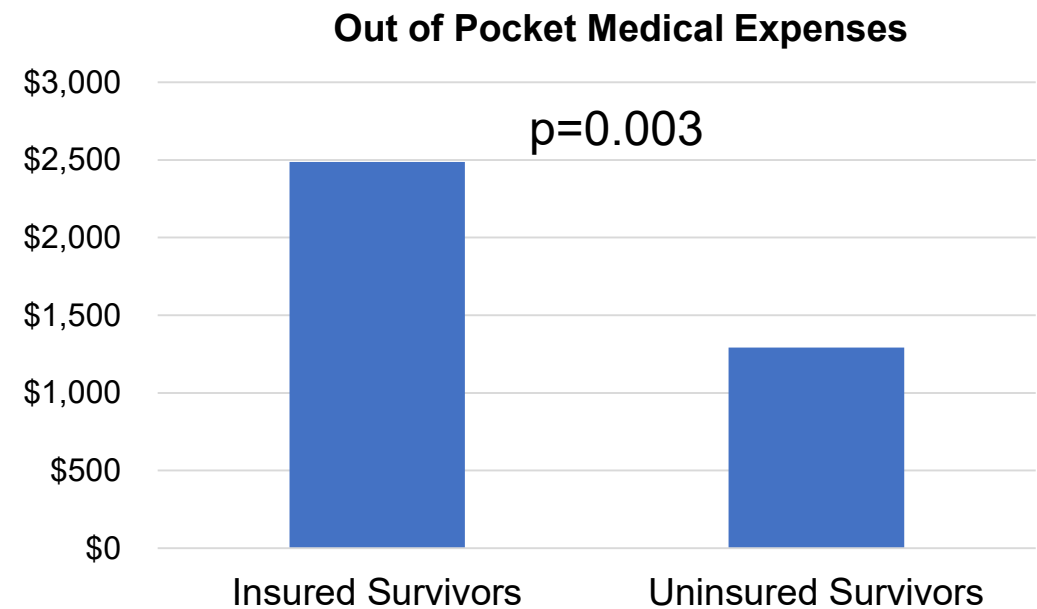
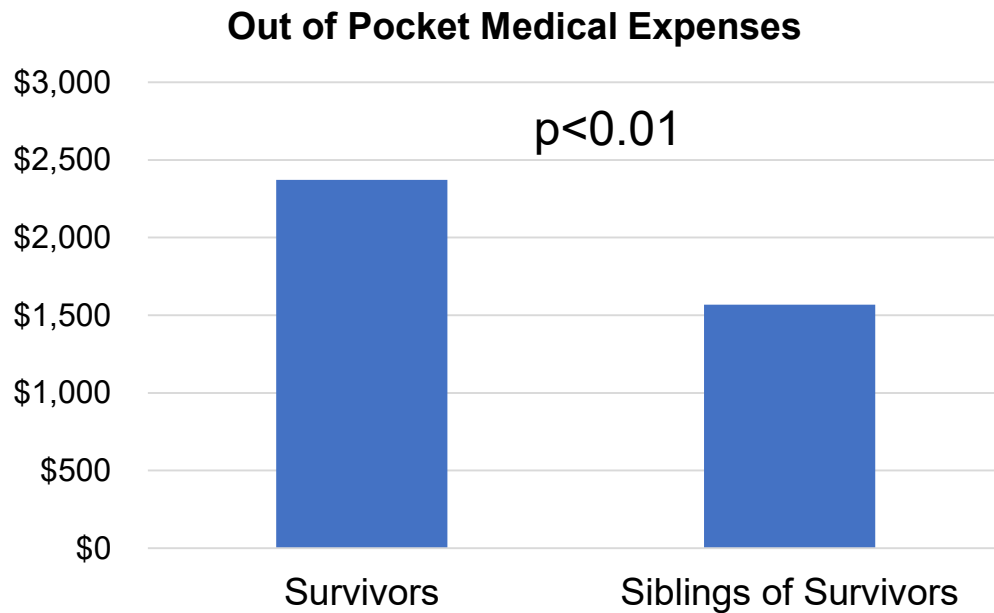
CCSS familiarity with ACA & legislation



Consequences of underinsurance ($\geq 10\%$ of income)



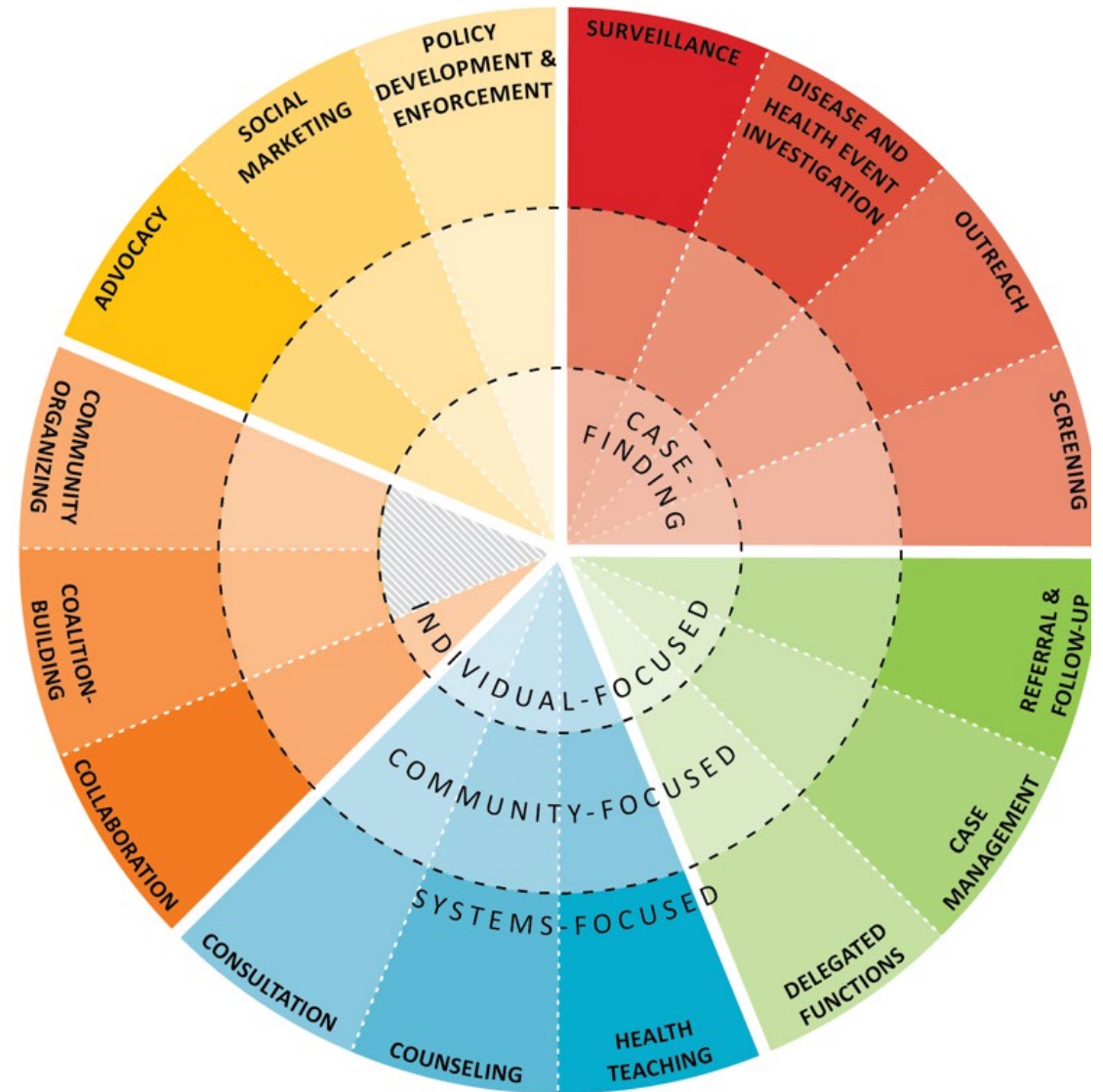
CCSS coverage, cost, and utilization



	Survivors	Siblings	OR (95% CI)
Had to borrow money	117 (17.3%)	18 (9.1%)	1.84 (1.03-3.28)
Worry about not being able to get a needed medical procedure	135 (20.6%)	27 (12.4%)	1.80 (1.09-2.98)
Did not fill a prescription	107 (15.7%)	19 (9.0%)	1.74 (1.01-3.04)

Interventions needed

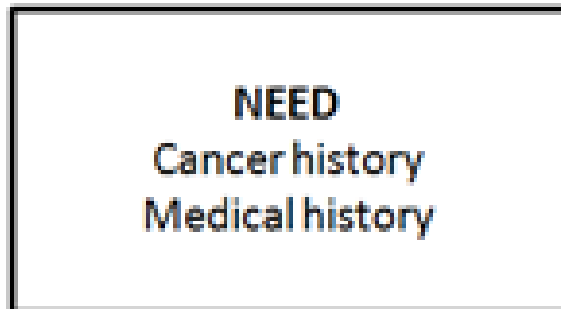
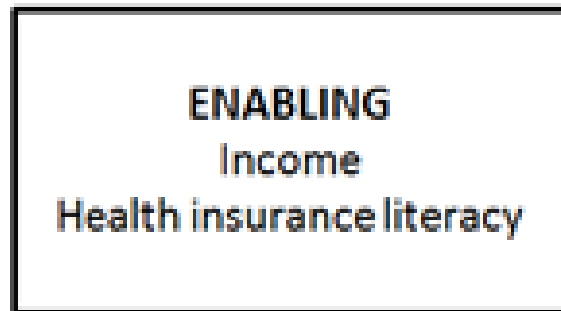
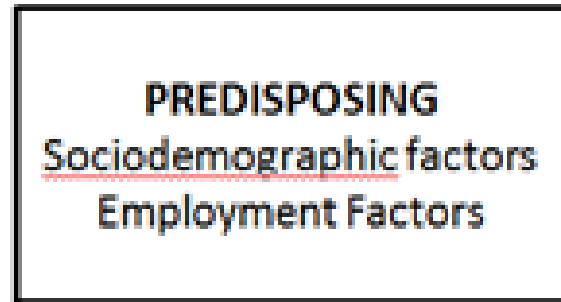
- **Public health intervention wheel**
Provides a framework for how to address intervention work needed
 - Community level (AYA advocacy organizations)
 - Systems level (how health insurance education is presented to AYAs and families; options to support enrollment into insurance coverage)
 - Individual level (our patient navigation intervention)



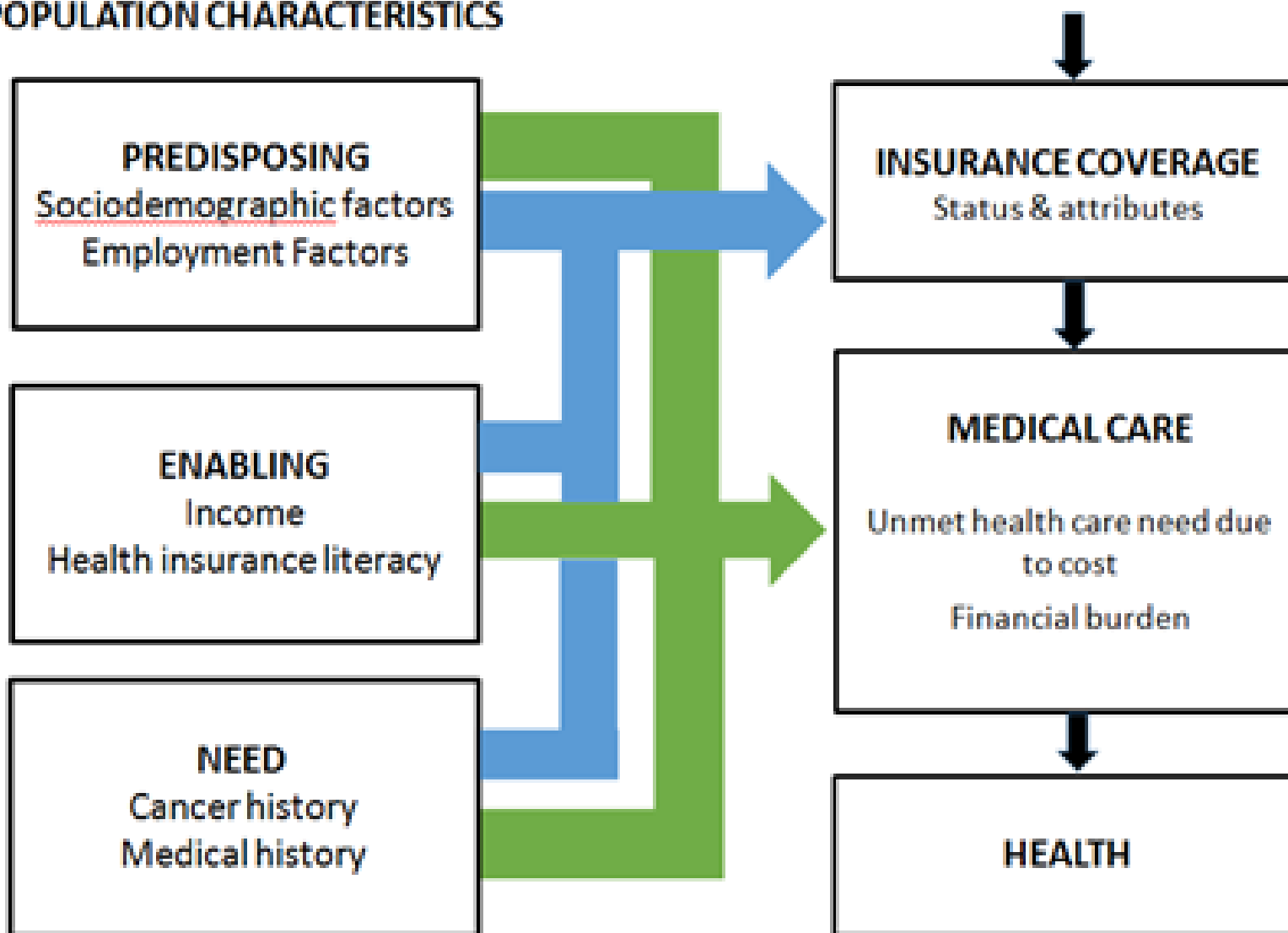
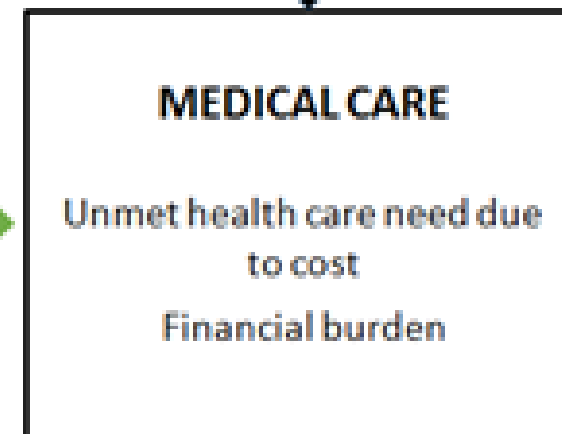
Conceptual Model

(Adapted from Levy & Meltzer and Andersen & Aday)

POPULATION CHARACTERISTICS



Policy and Structural Factors: ACA implementation



Health insurance literacy interventions



Adult survivors of pediatric and adolescent cancer from the Childhood Cancer Survivor Study
PI: Elyse Park



Adolescent and young adult cancer patients currently in cancer treatment
PI: Anne Kirchhoff

Session Content

Session 1: Learning about insurance concepts

- Informational: Types of insurance coverage & insurance terms
- Activity: Identifying out-of-pocket costs
- Resources: Summary sheet and list of terms

Session 2: Navigating one's insurance plan

- Informational: Private vs. public insurance; types of insurance
- Activity: How to read your insurance card, where to call with Qs
- Resources: Summary sheet and list of terms



Session Content

Session 3: Learning about legislation

- Informational: Affordable Care Act; Other policies (FMLA, ADA, COBRA)
- Resources: Summary sheet and list of terms

Session 4: Confidence in managing care costs

- Informational: Review of cost-sharing mechanisms; Tradeoffs (lower premium vs. higher out-of-pocket maximums); Cost conversations
- Activity: Budgeting and tracking tools
- Resources: Summary sheet and list of terms



Intervention Outcomes

- Efficacy: Assessed by the ACS's National Patient Navigator Leadership Summit recommended patient-navigation outcome measures
 - Includes: perceived knowledge, perceived confidence in overcoming barriers to care, and satisfaction with patient navigation services
- Measures:
 - Health insurance literacy
 - Financial distress related to medical costs
 - Familiarity with ACA policies





Health Insurance Navigation Tools

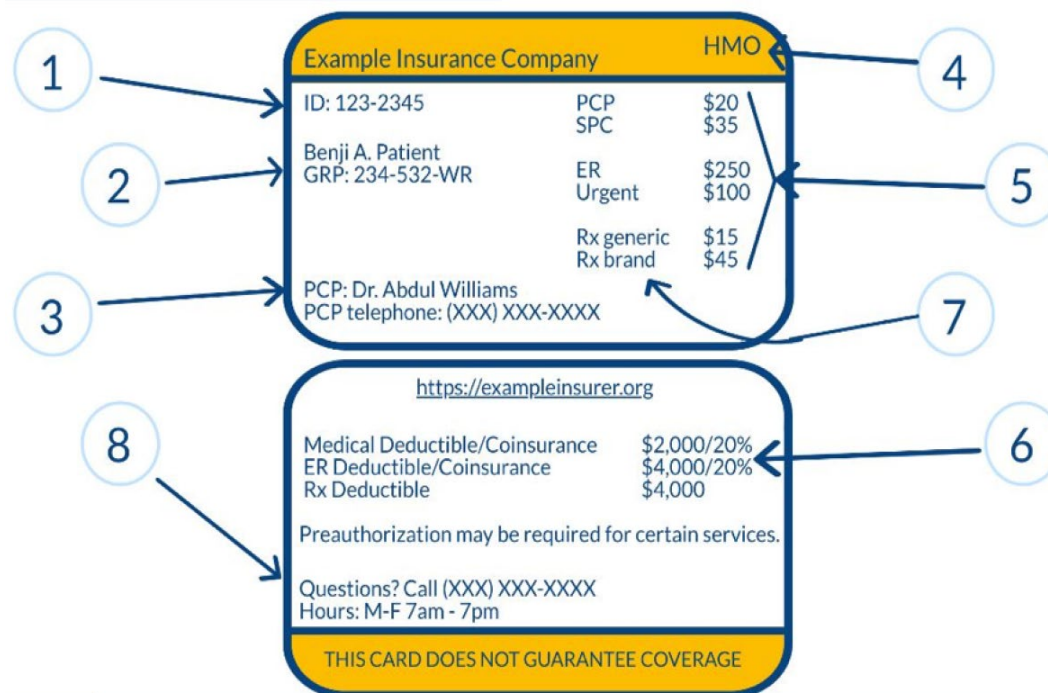
A Guide to Health Insurance

PARTICIPANT MANUAL

INTERNAL APPEAL REVIEW

Appeals that are filed to your insurance company to re-evaluate if the procedure, medication, or other service falls within your benefits and coverage. There are time frames for appeals to ensure treatment is not delayed for too long:

Type of Appeal	Reason for Appealing	When Patient Should Submit Appeal	Timeline for Decision from Insurer
Pre-Authorization Appeal	Denial before services rendered. Denial prevented patient from receiving care	Within 180 days	Within 30 days of initial appeal
Post-Treatment Appeal	Denial for payment of care received meaning patient is 100% responsible for any charges	Within 180 days	Within 60 days of appeal
Urgent Care (or Expedited) Appeal	Delay in treatment would seriously jeopardize life/overall health, affect your ability to regain maximum function or subject you to severe and intolerable pain	Within 180 days But if urgent can ask for external review at same time as internal review	Within 72 hours of receiving appeal



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THE BREAKDOWN

Here is the breakdown of Hazel's insurance plan...

Monthly Premium	\$60
Deductible	\$2000
Co-Payments	\$15 PCP; \$30 specialist
Co-Insurance	80/20 after deductible is met
Out-of-Pocket Maximum	\$4000

Health care coverage & use (NHIS)

Childhood Survivors vs. Controls: 2010-2014	Survivors	Controls	P-value
Has Health Insurance	76.4%	81.4%	0.07
Delayed Medical Care	24.7%	13.0%	<0.001
Needed but Did Not Receive Medical Care in Past 12 Mos	20.0%	10.0%	<0.001
Had Trouble Paying Medical Bills	40.3%	19.7%	<0.001

Adult Survivors: 2010-2016	Annual Proportion Decrease (Beta)	P-value
Delayed Medical Care	0.47	0.05
Needed but Did Not Receive Medical Care in Past 12 Mos	0.35	0.04
Unable to Afford Prescription Medication	0.66	0.004
Unable to Afford Medical Services	0.51	0.01

Research gaps and remaining challenges

- Determining rate of AYA's underinsurance and its effects on access to care:
 - ACA plans with narrow networks limit AYAs' access to care, including academic medical centers and clinical trials.
 - Most insurers do not cover oncofertility services, which are expensive and commonly needed by AYAs.
 - High deductible plans potentially delay care.
- Interventions are needed at the individual, community, and systems levels to improve AYAs' health insurance literacy and access to care

Thank you!

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