

Piloting a Patient-Driven Online Survey to Better Study Cancer in Adolescents and Young Adults (AYA) in the United States

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Disclosures

- I disclose that this work has been a team effort
- I have no financial conflicts of interest to report and no consultation fees.
- I disclose that all my money goes to my wife, 3 children and dog.



- The seed money for this project was from a generous grant from Hyundai "Hope on Wheels."
Gamsahamnida Hyundai!



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Introduction

- Adolescent and Young Adult (AYA) cancer patients aged 15-39 have demonstrated inferior survival improvements compared to older and younger patients over the last 30 years - *based on Surveillance, Epidemiology, and End Results (SEER) data.*
- The reasons for discrepancy is multifactorial and include:
 - Referral patterns
 - Low rates of clinical trial enrollment
 - Compliance
 - Lack of insurance
 - Delay in diagnosis
 - Low index of suspicion for cancer in AYA population
 - Poor understanding of biology of AYA malignancies
- 70,000 new AYA cancer patients are diagnosed every year in the United States.

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Introduction

- In 2006, the NCI with support from the Lance Armstrong Foundation (LIVESTRONG), convened a Progress Review Group on AYA cancer.
- This led to the first national cohort study of AYA cancer patients in the US, the **Adolescent and Young Adult Health Outcomes and Patient Experience (AYA HOPE) study.**
- Study participants diagnosed between ages 15 and 39 were identified from seven NCI SEER cancer registries
- A paper or internet survey was sent 6-14 mos. after diagnosis and 10-12 mos. later.

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Introduction

Findings

- Study participants ($n = 524$) were diagnosed between July 1, 2007 and October 31, 2008 with common AYA cancers.
- This was 43% of all eligible patients.
- Males were less likely to participate.
- 17% were still getting treatment at time of survey.
- AYA specialists evaluated responses and concluded 75% received appropriate treatment.
- Cancer type and clinical trial participation were associated with receiving appropriate treatment (<0.05).

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Introduction

Findings

- Appropriate treatment highest in sarcoma (79%) and lowest in ALL patients (56%)
- 17% were aware that there were clinical trials available for their cancer and 68% of those enrolled
- 13% were treated on a clinical trial
- 11% lost health insurance at some time
- Those without insurance reported worse quality of life (physical and mental health)
- 66% were treated at cancer centers
- Only 8% were academic and 2% pediatric – the rest received care at a community hospital/cancer center
- 30% of younger and 40% of older AYAs (>20) reported negative impact on plans for employment

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Introduction

Findings

- 72% in full time school reported returning to school
- More than 50% reported a negative impact on their plans for having children.
- Almost 65% said that cancer had a negative impact on their financial situation

This was the **first** population-based cancer registry to examine cancer care quality, physical and mental health outcomes for AYAs. It highlighted many gaps in knowledge of this population.

It has generated at least 17 manuscripts and is summarized in:
"Understanding care and outcomes in adolescent and young adults with Cancer: A review of the AYA HOPE study," Smith AW et al, Pediatric Blood and Cancer, Aug 2018.

This data is now over 10 years old. Time flies!

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Aims

- The Consortium of Adolescent and Young Adult Cancer Centers (CAYACC) was founded to create a partnership between centers who wanted to collaborate and better study this population.



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Aims



- Our first project together was to the creation of a unique database of self-reported patient health and psychosocial data to better study AYA cancer patients.
- We wanted a “snapshot” of AYA cancer care **today.**
- The goal of this study was to assess the feasibility of an opt-in, secure online survey to collect data from a larger landscape of AYA patients and survivors in the United States.

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Methods

- CAYACC created a 28-question anonymous survey for cancer patients and survivors diagnosed between the ages of 18 and 39 years.
 - The survey was approved through the Roswell Park Comprehensive Cancer Center’s IRB.
- Topics include:
 - Diagnosis
 - Treatment setting
 - Clinical trial access and enrollment
 - Insurance status
 - Social support
 - Fertility preservation utilization

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Methods

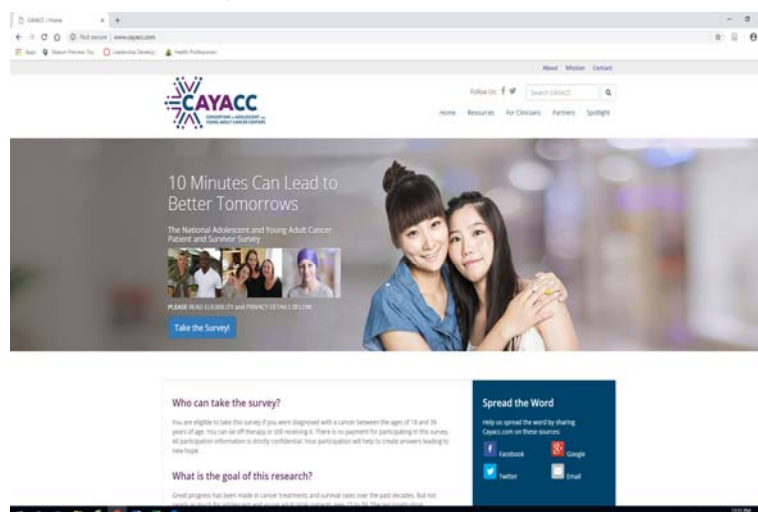
- The survey launched in April 2018 using social media and event outreach to reach out to colleagues and patients.
- Its initial goal was to reach 250 enrollments in 6 months
- We did not specifically recruit from our centers but instead recruited participants through AYA support organizations: TCA helped spread the word and we had a table exhibit at Stupid Cancer CancerCon 2018.
- Data was compiled through a website and is securely stored on a REDCap database through RPCCC.

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Our Portal

- <http://www.cayacc.com/>



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Results

Open from April 2018 - February 2019:

590 patients registered and 447 (76%) completed the survey.

Demographics:

- The majority (84%) were female
- Age range: 18-60 years
- 93% were white, 4% Hispanic/Latino, 4% Asian, 3% Black/African American, 1% Native American

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Results

Personal/family situation (at the time of the survey):

- 59% were married or living with a partner
- 36% were single and never married
- 5% were divorced or separated
- 46% were currently raising children under 18 y/o

Highest Level of Education Completed:

- 34% college graduate
- 34% post-graduate degree
- 15% had some college/vocational/training school
- 10% associate degree
- 5% were HS graduates but pursued/completed no further education

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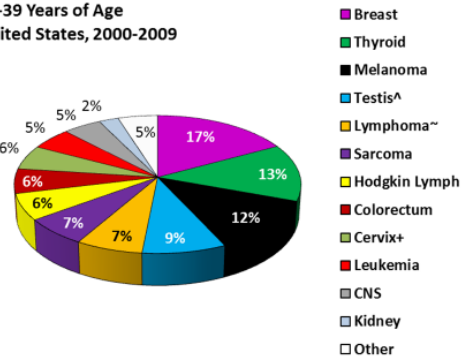
Results - Types of Cancer

CAYACC Survey

- 38% Breast cancers*
- 11% Leukemia *
- 11% Other/not listed
- 9% HD *
- 7% Sarcomas
- 5% Brain tumors
- 4% NHL#
- 4% Thyroid #
- 3% Testicular #
- 3% Colon #
- 2% Melanoma #
- 2% Ovarian
- 1% Cervical #

SEER Data

Top 12 Cancers in Adolescents and Young Adults
15-39 Years of Age
United States, 2000-2009



* CAYACC > SEER
SEER > CAYACC

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Results

How long were you experiencing symptoms before seeking care?

- 30% weeks
- 29% months
- 16% days
- 14% no symptoms – found on routine visit
- 10% 1 year or longer



JANUARY 2020						
Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
1	2	3	4	5	6	7
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22	23	24	25	26	27	28
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Results

Treatment setting:

- 58% did or were receiving care at a cancer center
- 13% did or were receiving care at a community hospital/clinic
- 11% did or were receiving care at a children's hospital
- 11% did or were receiving care at an adult oncology private practice



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Results

How did you choose primary oncology provider:

- 60% "My doctor referred me"
- **37% "I did my own research"**
- **21% "Shortest distance from home"**
- 17% "Insurance status influenced decision"



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Results

Quality of care:

- 82% described the quality of their cancer care as “very good” or “excellent”
- 12% good
- 6% described it as “fair” or “poor”



Are you currently receiving therapy?

- 41% yes

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Results

Were clinical trials available to you at diagnosis?

- **49% not sure**
- 29% yes
- 22% no



Interesting because the respondents were highly educated overall.

Have you ever participated in a clinical trial?

- 64% yes
- 35% no
- 1% don't know

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Results

Insurance status:

- 94% had insurance at diagnosis, however...
 - **12% reported that they had lapses in insurance coverage during or after treatment.**
- 83% responded that their insurance or lack of insurance did *not* influence where they chose their care.
- 98% reported currently being covered by health insurance

Source of Insurance:

- 76% through their employer/school or a partner or spouse's employer or school
- 12% Medicaid
- 11% parents
- 5% federal/state exchange (through ACA)

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Results

Were there any tests or treatments your MD recommended for cancer NOT COVERED by insurance?

- 35% yes
- 65% no

If not covered, did you receive the tests/treatments anyway?

- 77% yes
- 23% no



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Results

Knowledge about long-term side effects of therapy:

- 44% thought they had enough information
- 35% needed some more information
- 18% needed much more information

Knowledge about fertility risks of therapy:

- 46% thought they had enough information
- 22% needed some more information
- 10% needed much more information

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Results

Did someone at your treatment center discuss the potential impact of therapy on fertility?

- 73% yes
- 22% no
- 4% not sure



If offered sperm banking/ova/embryo cryopreservation, did you use these services?

- 64% no
- 14% banked sperm
- 14% froze ova
- 7% froze embryos
- 1% didn't remember (?)



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Results

The cost of sperm/egg/embryo freezing was too high for me:

- 52% disagree
- 48% agree

Preserving my fertility was not a priority for me at the time:

- 65% agree
- 35% disagree

Impact on plans for family:

- 33% very negative impact
- 29% somewhat negative impact
- 20% no impact
- 2% very positive impact

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Results

School/Employment status at time of diagnosis:

- 62% working full time
- 22% full-time student
- 16% working part-time
- 10% full-time homemaker/caregiver
- 4% part-time students
- 2% unemployed

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Results

School/employment impact of cancer diagnosis:

- 40% of those working took more than 2 weeks off
- 17% of those in school took more than 2 weeks off
- 24% stopped working completely
- 22% cancer had no impact
- 10% shifted work from full-time to part-time

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Results

Effect on education plans:

- 42% no impact
- 20% somewhat negative impact
- 20% did not apply
- 7% very negative impact
- 6% very positive impact
- 6% somewhat positive impact



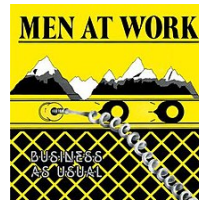
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Results

Effect on work plans:

- 39% somewhat negative impact
- 24% no impact
- 19% very negative impact
- 8% very positive impact
- 5% somewhat positive impact
- 5% does not apply



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Results

Financial impact:

- 49% somewhat negative impact
- 30% very negative impact
- 15% no impact
- 2% very positive impact
- 2% somewhat positive impact
- 2% does not apply



Received professional advice to help figure out payment of healthcare?

- 73% no
- 27% yes

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Results

Who provided medical care/emotional support?

- **77% mother**
- 60% friend
- 54% father
- 36% sister
- 22% brother
- 12% boyfriend/girlfriend
- 7% step-father
- 5% step-mother
- 2% no one



This was interesting because 59% were married or living with a partner

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Results

Participated in an **in person** support group?

- 61% no
- 39% yes



Participated in an **online or social media** support group?

- 62% yes
- 38% no

Saw a mental health worker **in person**?

- 55% yes
- 45% no

Saw a mental health worker **by phone/online/telemedicine**?

- 89% no
- 11% yes

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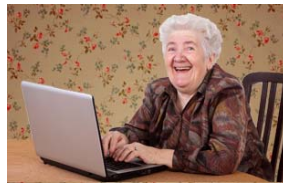
Results

Communication:

Check all the ways you prefer to receive communication and information about services available to you in your area?

(can check more than one)

- 86% email
- 49% Facebook
- 47% postal mail
- 16% Instagram
- 8% Twitter
- 2% Pinterest



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Conclusions

- Our respondents were predominantly female, white, well-insured and well-educated.
- There was also a greater percentage of respondents with breast cancer vs SEER data.
- This is another unique snapshot of the AYA population in the United States right now, and it will add to our body of knowledge.
- There is much analysis to be done comparing our findings with AYA HOPE data as well as other published AYA studies.

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Conclusions

- Our results demonstrate the feasibility of a patient-driven survey to complement SEER-based research.
- This tool should accelerate tracking of AYA cancer populations and create additional databases of information.
- We are analyzing the data for publication...



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Next Steps

- CAYACC's goal is to use this data as a foundation for further research on this uniquely challenged population of patients.

We can do this by:

- Expanding the next survey's depth
- Expanding the next survey's reach through more aggressive marketing to obtain a greater cross-section of AYA patients in the U.S.
- Increasing the number of centers in CAYACC as we further define our mission beyond the survey.

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Thanks to my Fellow CAYACCers!

- Lynda K. Beaupin, MD



- Scott C. Borinstein, MD, PhD



- Damon R. Reed, MD



- Nicholas D. Yeager, MD



- John C. Senall



- Denise Rotitka, MD



- Odochi Uwazurike, BA



- Jennifer Schweitzer, BA, MS

