



# AYA Oncology in the 21<sup>st</sup> Century: Psychosocial Context

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## Disclosures

No financial relationship(s) or  
conflicts of interest to disclose



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## But Medicaid does...



President Clinton signs Omnibus Budget Reconciliation Act (OBRA), August 10, 1993



*"Medicaid Auctions"*

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## Estate Recovery, as per OBRA



President Clinton signs Omnibus Budget Reconciliation Act (OBRA), August 10, 1993

- States must recover Medicaid benefits paid on behalf of an enrollee for nursing facility services, home and community based services, and related hospital and prescription drug services
- Action by state government to collect money from the estate of a deceased Medicaid patient (over age 55 yrs)
- Allows pre-death liens (claims) on income and assets, tacking interest onto past-due debts, limiting hardship waivers; collection and sale of personal property; can claim estate benefits from deceased patients

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## Financial Impact of Cancer is a PROBLEM

Among 9.5 million people diagnosed with cancer in the U.S. between 2000 to 2012:

- **42%** drained their financial assets within **2 years**
- *Across the population, the average patient experienced a loss of \$92,098.*

(Gilligan et al., 2018)

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## What are the Causes of “Cancer-Related Financial Toxicity”



**Costs  
of Care**

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Commentary

## Financial toxicity of cancer treatment: Moving the discussion from acknowledgement of the problem to identifying solutions

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[TheLancet.com](https://www.thelancet.com),  
January, 2020

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***Moving from problem to solution means putting the problem into context***

***Financial Toxicity is NOT a clinical issue***

***Financial Toxicity is a population health and social issue***

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## AYA in the USA: Population Health and Social Context

Brad Zebrack, PhD, MSW, MPH

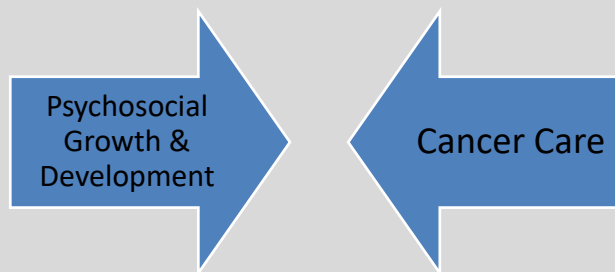
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## Nature 554, (2018)



- “Snow and adolescence are the only problems that disappear if ignored for long enough.”
- More informed and thoughtful approaches are needed to study and address cognitive and social changes that happen during adolescence, and to design effective interventions.
- Interventions must be informed by EVIDENCE of the world around us

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**Understanding the behavioral, social, and environmental context of AYAs' lives is critical for delivery of cancer care**

Adherence to or completion of therapy  
Symptom-management  
Doctor-Patient Relationship  
Clinical trials recruitment and retention  
Quality of Life

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## Developmental Tasks of Adolescence / Young Adulthood

- Establishing independence
- Forming identity, becoming comfortable with who you are
- Relationships (friends, family, love)
- Beginning own family
- Jobs and careers
- Finding their place in the world
- Making choices

Arnett, 2000



Jaden Smith



Millennials (1981-1997)  
Taylor Swift



Gen Z (1998-2020)  
Yara Shahidi

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Perspectives

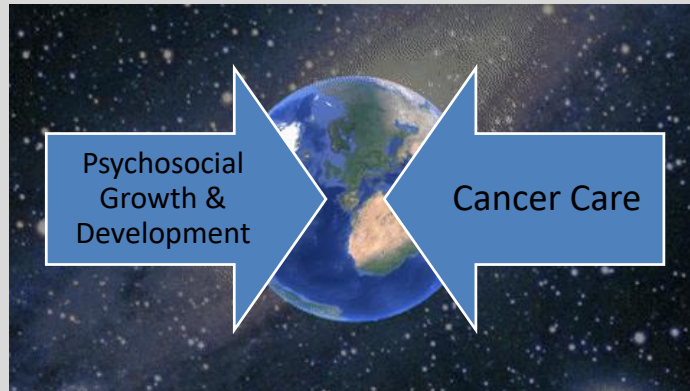
### Against a Singular Message of Distinctness: Challenging Dominant Representations of Adolescents and Young Adults in Oncology

Chad Hammond, PhD

*“AYAs around the world face increasing  
vulnerability and ambiguity in their daily lives”*

*“Developmental pathways are interlinked with  
social and material conditions of life”*

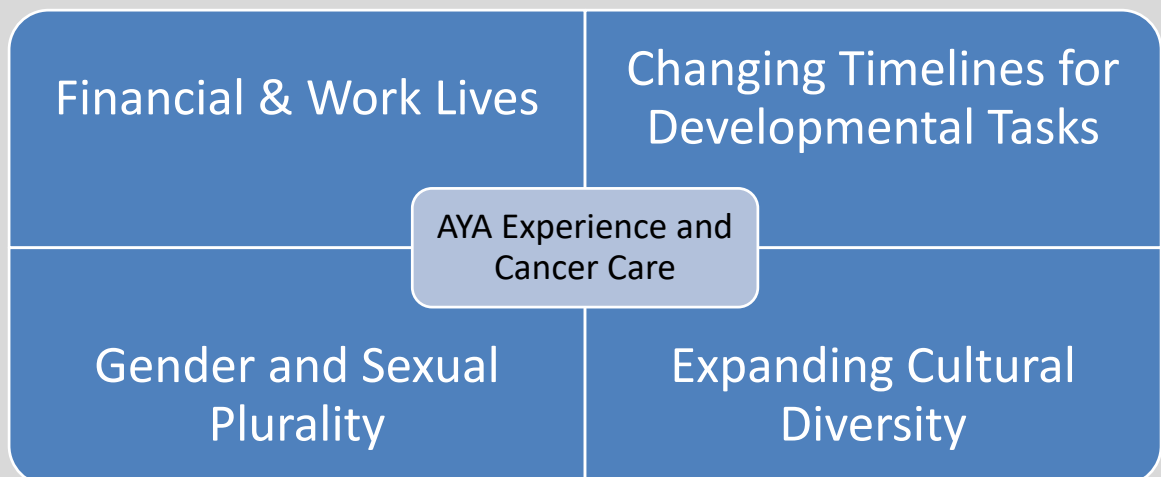
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## AYA IN SOCIAL & GLOBAL CONTEXT

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## AYA in the 21<sup>st</sup> Century The Millennial / Gen Z Experience



Hammond, JAYAO, 2016

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# 1. Financial and Work Lives

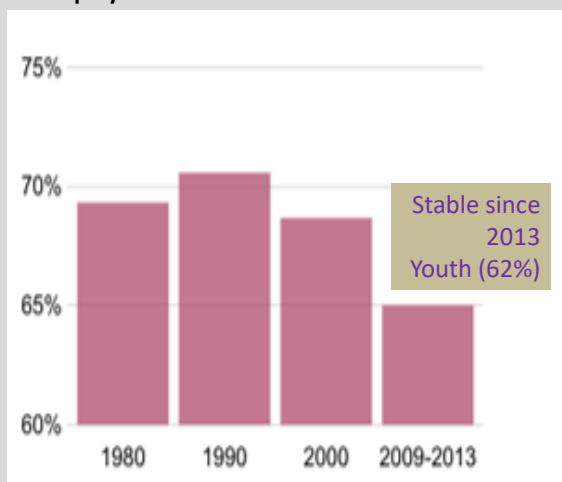
- Lack of stable, secure jobs that utilize educational qualifications or offer sense of work-related identity
- High tuition, unaffordable mortgages, student loan debt
- Fewer non-wage benefits (e.g., health insurance, retirement, paid leave) – “Gig Economy”
- Reductions in social safety nets, public services
  - General Assistance, Food Stamps, Medicaid, Disability benefits contribute to further impoverishment (Edin & Shaefer, 2016)



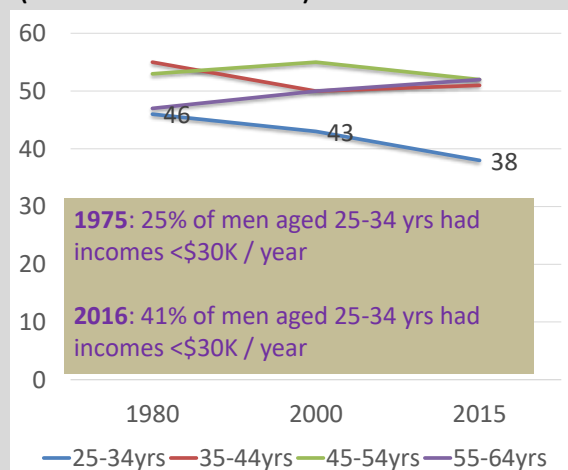
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## Labor Force, Ages 18-34yrs (US Census Bureau)

Employed Population, Age 18-34yrs  
% employed



Median Earning (Full-Time Year Round)  
(2015 Dollars in Thousands)



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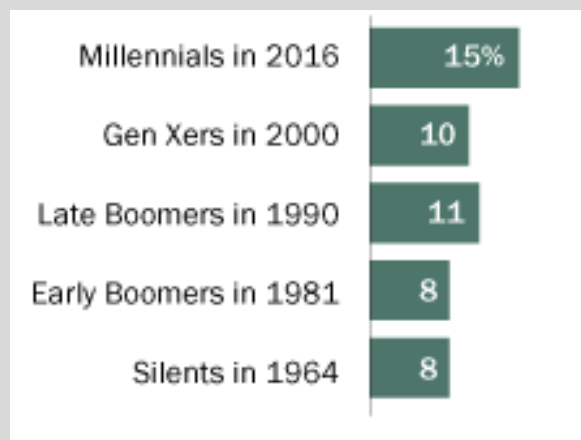
## Hidden story

- Economic opportunities disproportionately located in major cities
  - Those with resources move; those without do not
- High housing costs
  - Average rent/month
    - NYC (\$3432); Los Angeles (\$2546); Chicago (\$1947); San Antonio (\$1039); St. Louis (\$953)
  - Affordable housing not aligned with location of job opportunities
    - ¼ of renters spend 50% of income on housing
    - Most spend 30-40% of income on housing
- Transportation cost increase (time, distance to work)

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## 2. Changing AYA Timelines and Priorities

- Economic instability is delaying and deferring dating, marriage, parenthood, employment, independent living
- Deferring “normative” developmental tasks as choice
  - Reinforced by their peers
  - Not experienced as “delays in development” or “psychological regression”

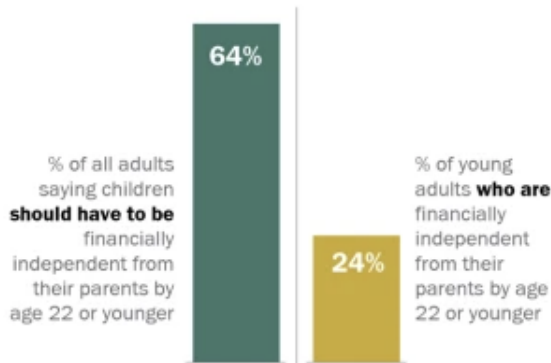


% of 25-35 year olds living in parent(s)' home

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## (In)Dependence

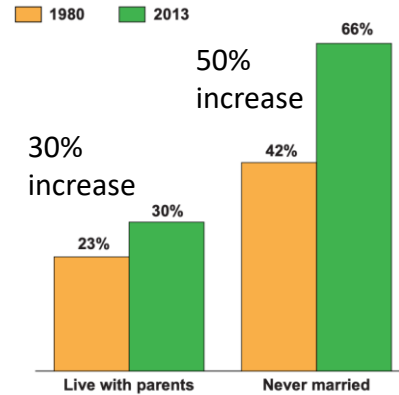
**Most say young adults should be financially independent by age 22, but reality differs for many**



Pew Research Center

**Today, More Young Adults Live With Parents and Are Never Married**

Percent of 18–34 Year Olds in:



United States Census Bureau

U.S. Department of Commerce  
Economics and Statistics Administration  
U.S. Census Bureau  
census.gov

Source: U.S. Census Bureau, American Community Survey, 2009–2013 and decennial census 1980, 1990, 2000.

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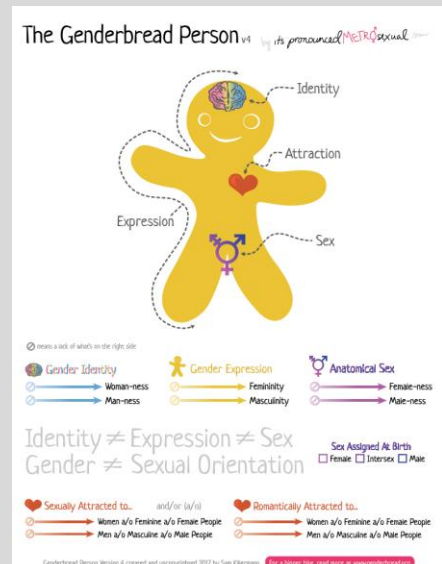
## 3. Gender and Sexual Plurality

Better understanding of the SCIENCE of human sexuality

Sex ≠ Gender

Social norms changing

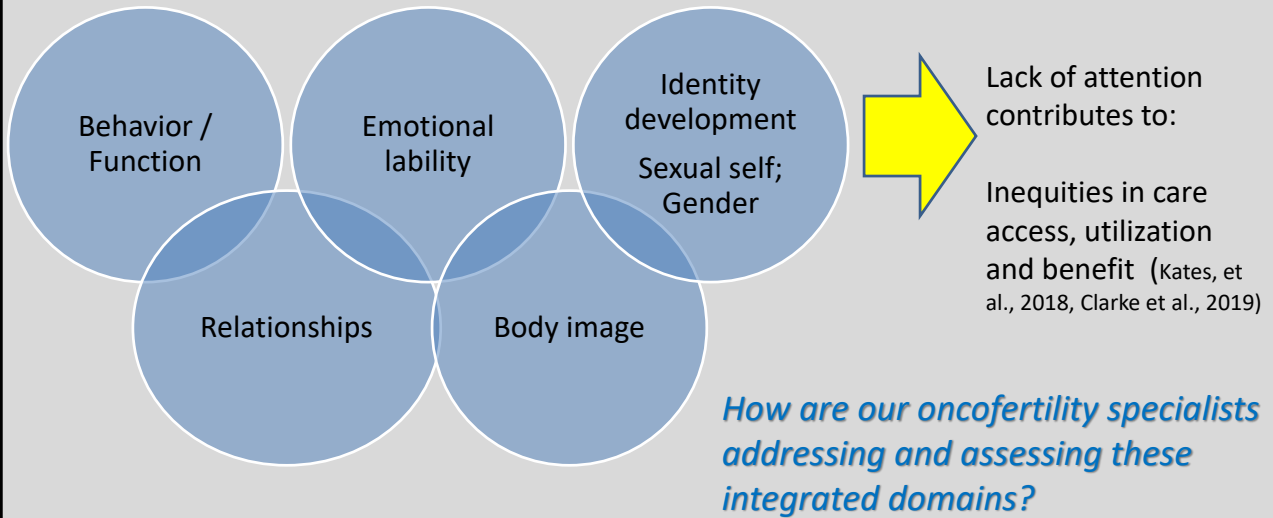
- More open communication and dialogue: sexual attraction, family composition, gender identity
- Yet, active discrimination and violence still exist



Yarber & Sayad (Eds), Human Sexuality, McGraw Hill, 2016.

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## Sex, Sexuality, Reproductive Health



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## 4. Expanding Cultural Diversity

### Race/ethnicity in 2017

White Hispanic Black Asian Other

**Millennials**  
Ages 21 to 36  
Born 1981-96

White	56%	21	13	7	3
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**Gen Xers**  
Ages 37 to 52  
Born 1965-80

White	61%	18	12	7	2
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**Boomers**  
Ages 53 to 71  
Born 1946-64

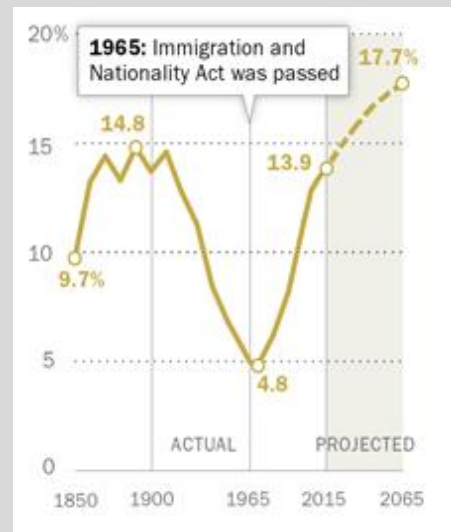
White	72%	11	11	5	2
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**Silents/Greatest**  
Ages 72 and older  
Born before 1946

White	79%	8	8	5	1
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Note: Ages shown are as of 2017. Members of the Silent Generation were ages 72 to 89 in 2017. Since the Current Population Survey aggregates those ages 85 and older into one category, outcomes for members of the Silent and Greatest generations cannot be separately shown. Whites, blacks and Asians include only single-race non-Hispanics. Hispanics are of any race. Asians include Pacific Islanders. "Other races" includes non-Hispanics of other races and non-Hispanics who identify with multiple races. Figures may not add to 100% due to rounding.

44% of US citizens 18-34yrs report race as other than non-Hispanic White, US Census Bureau



US Foreign-born share projected to hit record milestone by 2065, Pew Research Center

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## Against a Singular Message of Distinctness: Challenging Dominant Representations of Adolescents and Young Adults in Oncology

Chad Hammond, PhD

### Why we need Precision Medicine for AYA Care PSYCHOSOCIAL CONTEXT

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## Consider: Exposures to Emotional Trauma

### Adverse Childhood Experiences (ACEs)

“All types of abuse, neglect, and other potentially traumatic experiences that occur to people under the age of 18.”

- CDC, 2016



*39% adults reported  
being verbally  
abused one or more  
times as a child*



*20% adults reported  
mental illness in  
their household  
growing up*



*27% adults reported  
having separated or  
divorced parents*

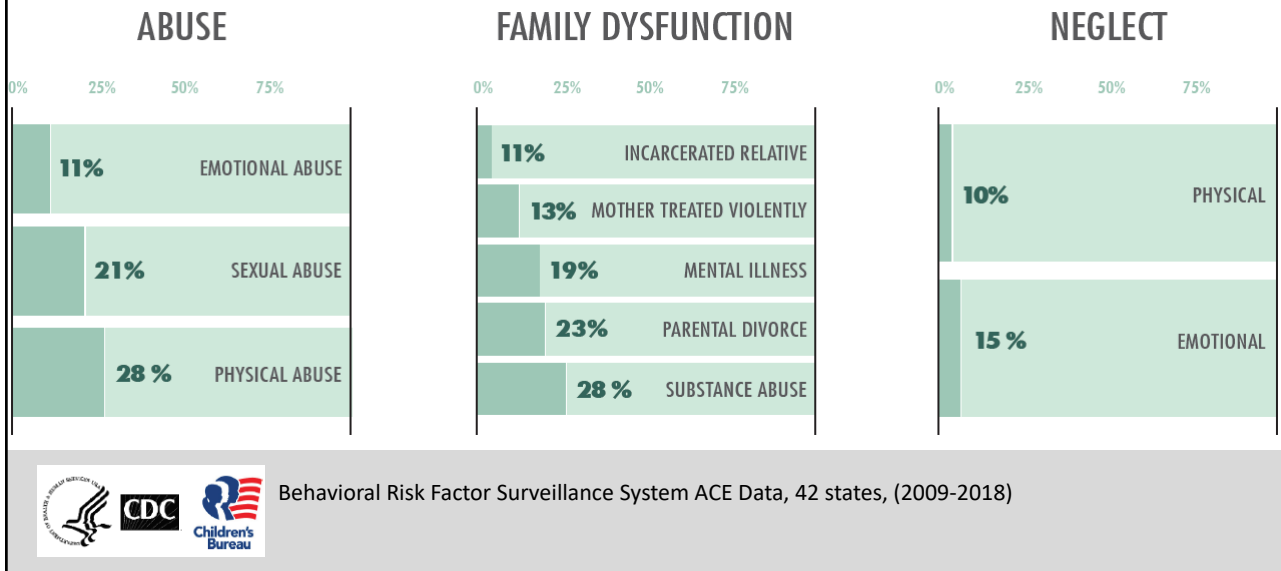


*19% adults reported  
witnessing physical  
violence between  
adults in their  
household*

2016 Behavioral Risk Factor Survey, State of Michigan data;  
follow up to CDC Kaiser ACES study; n=17,000 (1995-1997)

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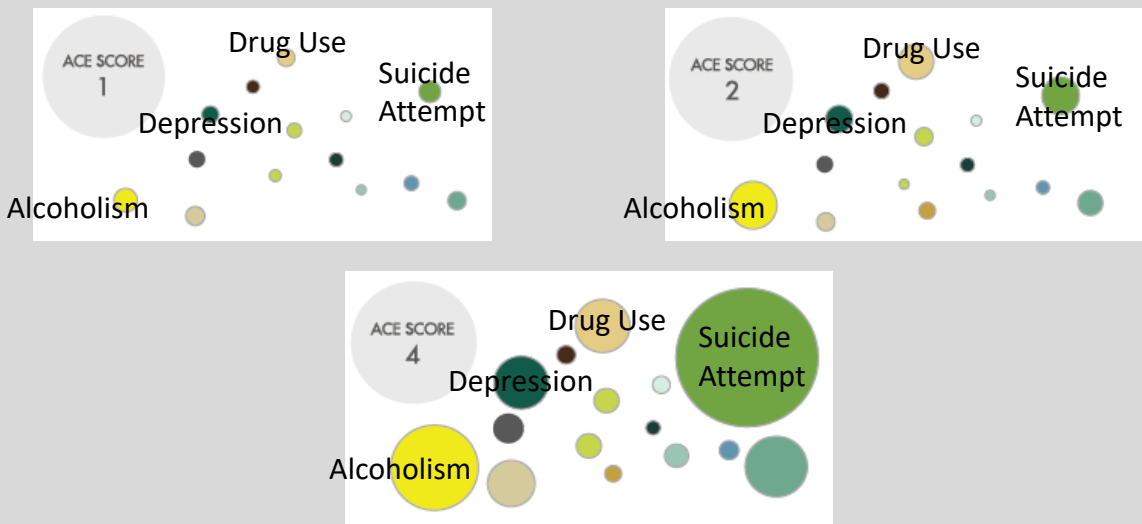
## Emotional Trauma – Adverse Childhood Experiences (ACEs)



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## Dose-Response

Likelihood of experiencing specified behaviors or health outcomes



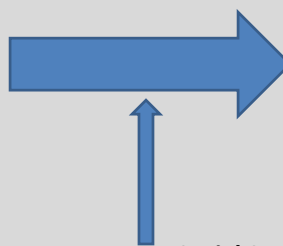
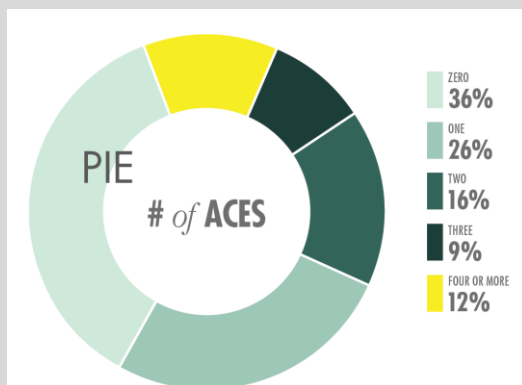
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## Clinical Significance -- Emotional Trauma

- Emotional and behavioral manifestation of childhood trauma exposure may not occur until adolescence or young adulthood
- Manifest as unsafe sexual behavior, drug/alcohol abuse, psychiatric symptoms, suicide, non-adherence to therapy

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## Social Support Matters



- Risky behavior
- Poorer health outcomes

### Social Support

Belonging  
Supported by friends  
Other adults in life  
Talk with family about feelings  
Participate in community traditions  
Feel like family stands by me during difficult times

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## AYA Research & Practice in the 21<sup>st</sup> Century Opportunities and Challenges



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### 1. Are our interventions meeting AYAs' needs and preferences?

- Most interventions for AYAs delivered during treatment
  - Yet, transition to off-treatment is critical time point
  - Little known about End-of-Life needs
    - 17%-20% mortality rate at 2-5 years post-diagnosis

Walker, Martins, Aldiss, Gibson, & Taylor, 2016

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## Are our interventions meeting AYAs' needs and preferences?

- To determine efficacy and effectiveness – Consider Precision Medicine:
  - Who are patients “at risk”?
  - Who most likely to benefit?
  - What are optimal modes of intervention delivery (face-to-face; Internet)?
  - Format (individual, peer survivor group, family)?
  - “Dosage” – for how long?

Walker, Martins, Aldiss, Gibson, & Taylor, 2016

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## Role for Technology?

### PROS

- 99% Prevalence of Internet Use in AYAs (*Pew, 2018*)
- Technologically-delivered interventions may be more feasible for AYAs (*Rabin, 2013*)
- Unmet psychosocial needs are attributable to limited availability of services using telecommunication technologies, (e.g., mobile devices, social media, internet) (*Joint Task Force Development of Telepsychology, 2013*)

### CONS

- FOMO (anxiety), worse subjective well-being attributable to social media (*Kross et al., PLOS One, 2013*)
- Greater screen time associated with increased depressive symptoms, suicide risk & reductions in well-being (*Twenge et al., 2017*)
- Limited use of social media associated with reductions in loneliness and depression (*Hunt, et al., 2018*)

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## Self-efficacy → Quality of Life

Confidence and competence in performing a given task, or performing within a given domain, such as managing the effects of cancer and its treatment.

A. Bandura



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## Self-efficacy for coping with cancer Merluzzi et al., 2001

- *Maintain activity and independence*
- *Seek and understand medical information*
- *Stress management*
- *Cope with treatment-related side effects*
- *Accept cancer and maintain a positive attitude*
- *Affect (emotion) regulation*
- *Seek support*

**Intimate relationships**

**Family**

**Neighborhoods / Communities**

**Nations**

**Global Trends**

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## Opportunities Ahead

- Identify and harness the intellectual, social and political capital of our constituency
- Engage and foster communication and interaction
  - Scientists (Medical, Social, Behavioral)
  - Clinicians
  - Patients and Families
  - Advocates / Stakeholders
- Conceptualize and implement solutions at multiple levels
  - Patient
  - Provider
  - System
  - Population



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