

Unmet psychosocial needs and gaps in knowledge in the care of adolescent and young adult patients with cancer

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Disclosure information

- I have no relevant financial relationships to disclose.

- AND -

- I will not discuss off label use or investigational use in my presentation.

Outline

- Define and describe AYA oncology
- Describe basic domains of psychosocial care
- Demonstrate knowledge gaps in psychosocial care



What age range is adolescent young adulthood?



Depends on where you live . . .

- SEER: 15-29
- NCI: 15-39
- Canada: 15-29
- Australia: 15-25
- UK: 13-24
- Europe: 15-24

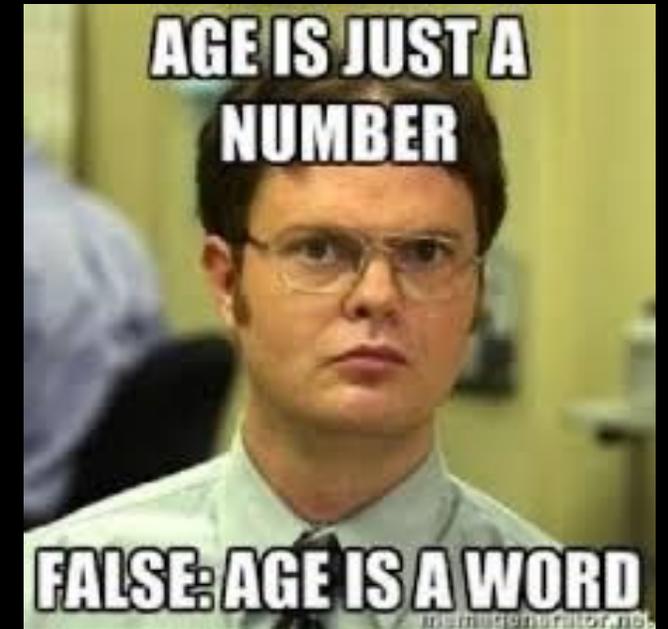


What should we use then?

More importantly . . . Am I still a young adult?!?!?!?

AYA Definition

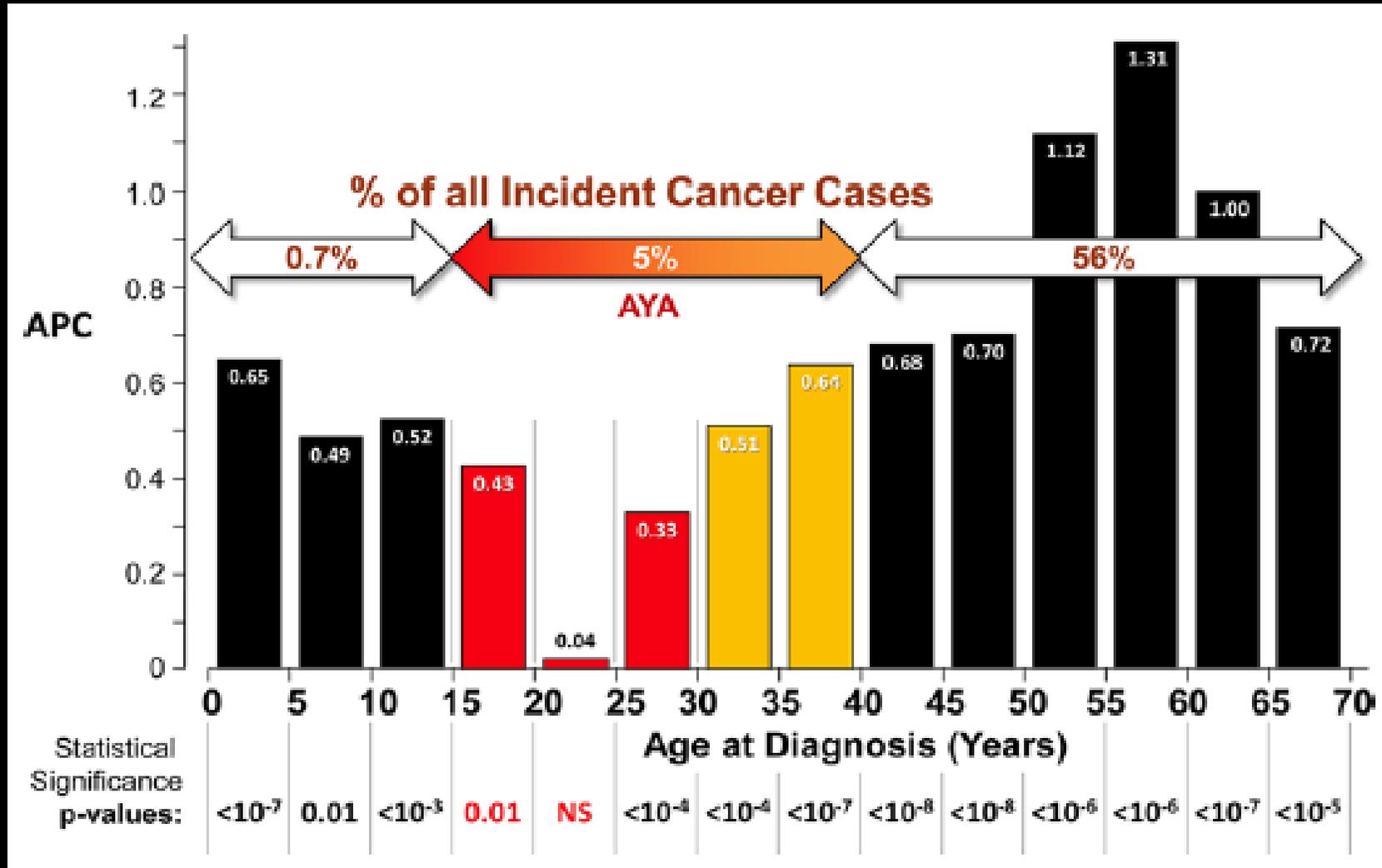
- Formally considered 15-39 in the United States
 - Early young adulthood 15-18
 - Young adulthood 19-24
 - Late young adulthood 25-39



Current state

- ~89,500 new diagnoses per year in the US
- Over 1 million new diagnoses per year globally
- Incidence is increasing slowly
- Leading cause of disease related death in AYAs

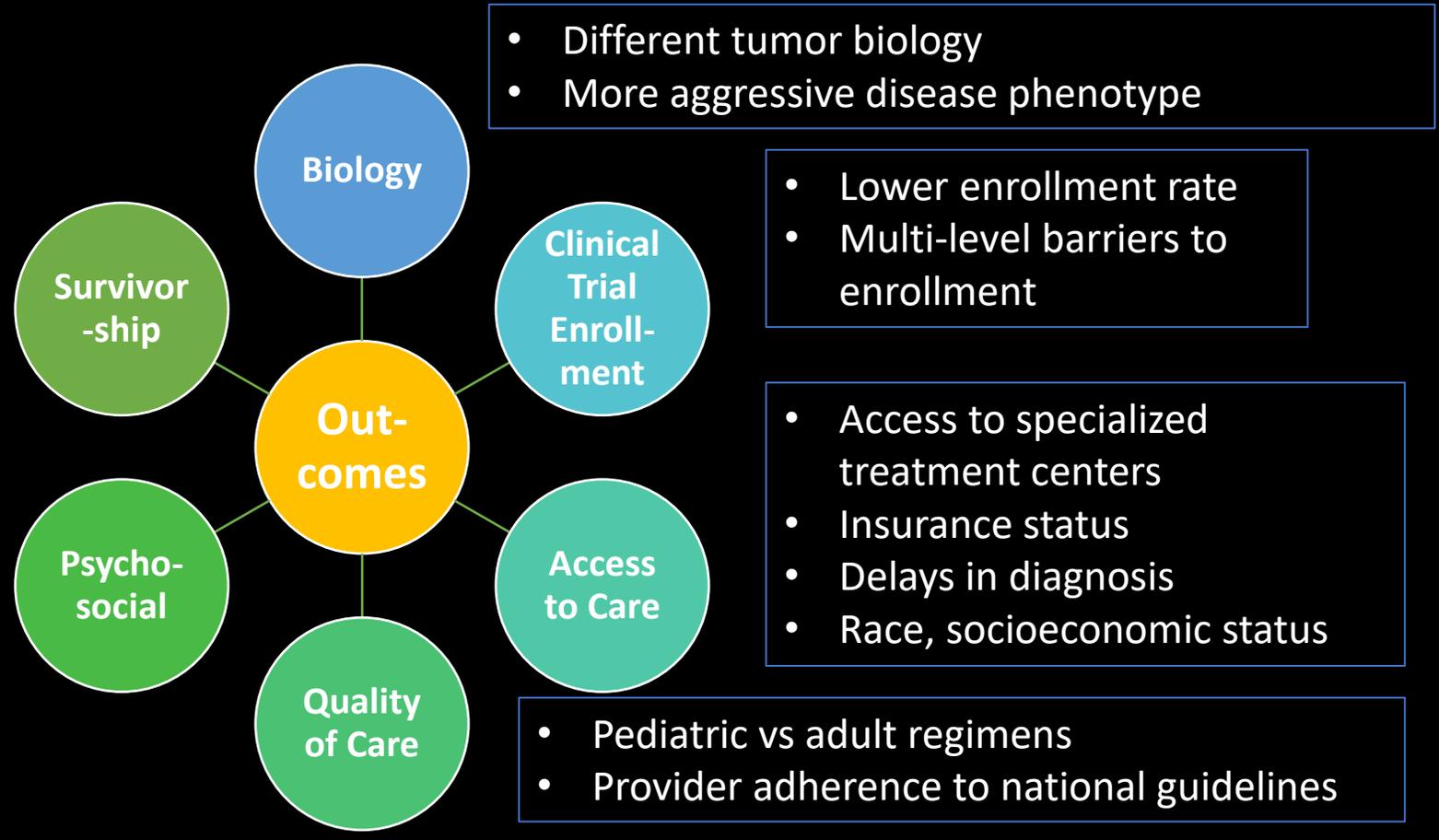
Current state



Factors contributing to the disparity in AYA health outcomes

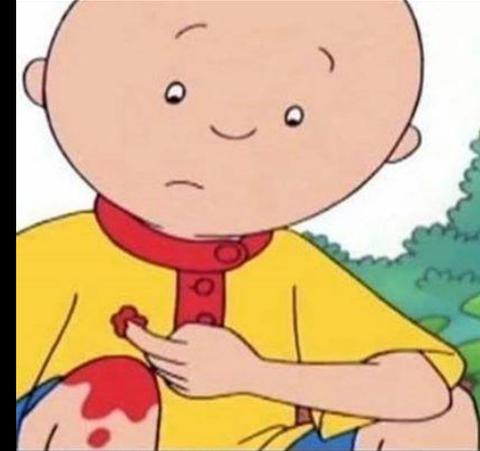
- Long-term health complications (e.g. cardiomyopathy)
- Fertility issues
- Poorer health-related quality of life
- Ongoing psychosocial issues

- Education & career goals on hold
- Employment & income concerns
- Loss of autonomy
- Self-esteem issues
- Social isolation
- Social & romantic relationships
- Mental health issues (e.g. depression, PTSD)



AYA Specific Issues

- “Delays” in diagnosis
- Financial toxicity
- Location of therapy



Childhood injuries:

Fell off my bike
Fell out of a tree
Twisted my ankle



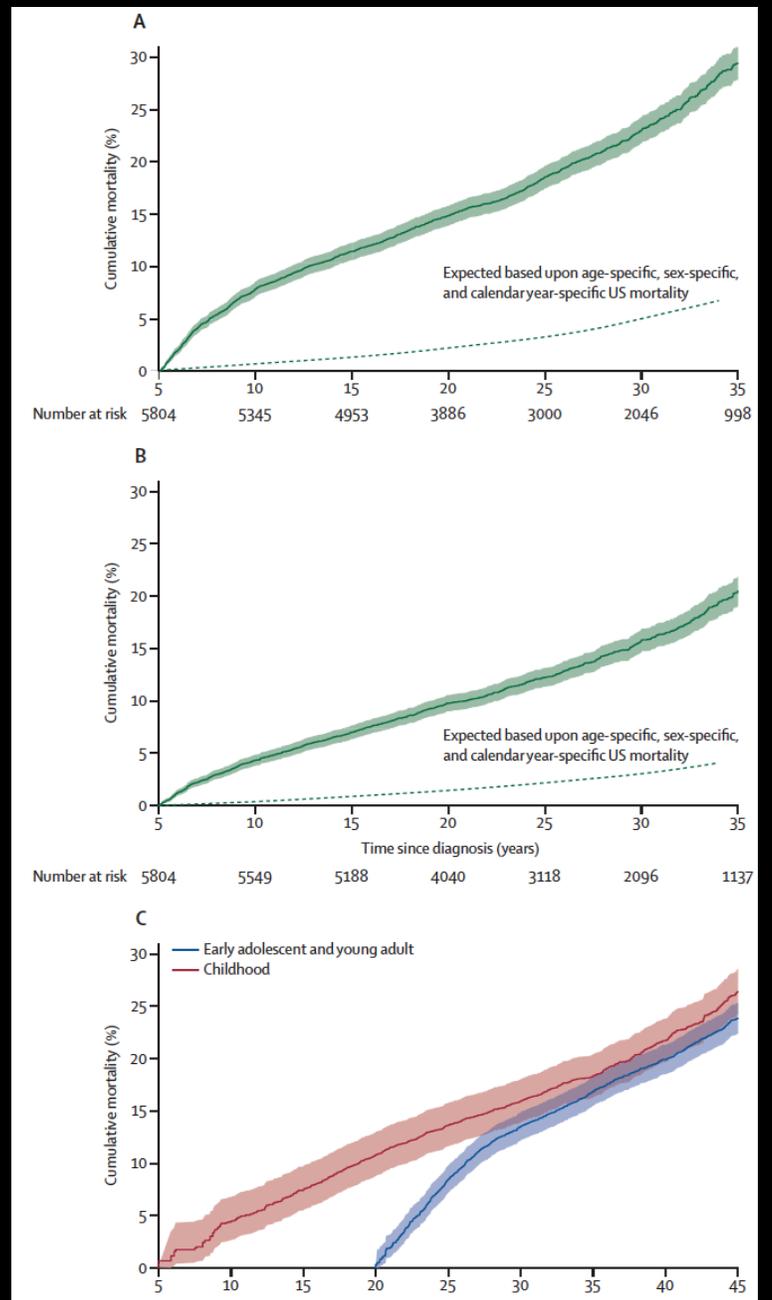
Adult injuries:

Slept wrong
Sat down too long
Sneezed too hard

MemeZilla.com

AYA Specific Issues

- Clinical trial enrollment
- Adherence to therapy
- Rehabilitation and exercise
- Transitions in management



AYA Specific Issues

- Palliative and end of life care
- Psychological support



AYA Specific Issues

- Oncofertility
- Sexuality, relationships, and body image



What is “it” . . .

- Sexuality is the complex interrelationship between:
 - Biological sex
 - Physical and physiological mechanisms of the sexed body
 - Body image
 - Sexual identity
 - Sexual orientation
 - Capacity for sexual expression
 - Interpersonal relationships

Why is it important?

- A satisfactory sexual life is important for health and well-being
- Sexuality is a central aspect of being human throughout life
- “Complications with [. . .] healthy sexuality have lifelong and serious ramifications”
- Sexual dysfunction is associated with worse general happiness

Why is it important?

- Adolescent survivors of childhood cancers have similar development
- AYAs with cancer do not
- Psychosexual development happens during the adolescent young adult (AYA) years
- Exposure to sexuality when not prepared causes trauma

Murphy et al *Cancer* 2015

Klosky et al *J Ped Psychol* 2012

Shandra et al *J Youth Adolesc* 2012

Frederick et al *Ped Blood & Cancer* 2018

What do AYAs think?

- Sexuality is a concern at the time of diagnosis and during treatment
- Friends and peers are the first choice
- It can effect any part of cancer therapy



What do AYAs think?

- Sexuality is considered “good”

SEX POSITIVE (*adj.*) —

Comfortable with one’s own sexual identity and with the sexual behaviors of others, with the purpose of promoting healthy, smart, safe and consensual sex.



What do AYAs think?

- AYAs want better communication with doctors about sexuality
- AYAs with cancer have mentioned oncologist



What do AYAs think?

- Vulnerable populations are even more at risk
 - LGBTQ with cancer report negative experiences
 - Report being discriminated against
 - Only 1/3 disclosed their orientation

Barriers to discussing reproductive health and sexuality

- Overshadowing focus on survival
- Misperceptions regarding AYA sexuality and cancer
- Presence of parents
- Clinicians are uncomfortable

AYAs on active therapy

- “Similar but different”
- Well established that AYAs with cancer have increased isolation and lower self-worth compared to peers



AYAs on active therapy

- Not enough experience to discuss adequately
- Not confident enough to engage in relationships
- Cancer patient as asexual and/or as “damaged goods”
- Greater sexual health concerns compared with healthy AYAs
- Single AYAs have worse sexual outcome than coupled

Survivors of AYA cancer

- Difficulties with disclosure of cancer
- Cohabitation and marriage rates lower than age-matched controls
- Stable employment lower than age-matched controls

1654 Beyond Mortality: Health-Related Quality of Life in Adolescent and Young Adult Patients with Lymphoma: A Longitudinal Study

Program: Oral and Poster Abstracts

Session: 905. Outcomes Research—Malignant Conditions (Lymphoid Disease): Poster I

Hematology Disease Topics & Pathways:

Young Adult, Study Population

Saturday, December 5, 2020, 7:00 AM-3:30 PM

Carla Casulo, MD¹, Tanzy Love, PhD^{2}, Xiang Lu, PhD^{2*}, Melissa C. Larson, MS^{3*}, Kathleen J. Yost, PhD^{4*}, Allison C. Rosenthal, D.O.⁵, Thomas M. Habermann, MD⁶, Brian K. Link, MD⁷, Andrew L. Feldman, MD⁸, Susan L. Slager, PhD^{4*}, Jonathon B. Cohen, MD, MS⁹, Christopher Flowers, MD, MS¹⁰, James R. Cerhan, MD, PhD⁶ and Carrie A. Thompson, MD⁶*

- Emotional, physical, and functional well being improves over time
- Social and family well being scores worsen over time

University of Chicago AYA Oncology Program

Mission

We aim to improve the outcomes and quality of life of every adolescent and young adult (AYA) cancer patient and survivor through team-based, comprehensive, collaborative care addressing the unique medical and psychosocial needs of AYAs.

Vision

Our program aims to improve the life of every AYA cancer patient and survivor locally while leading the world in revolutionizing AYA oncology by:

- Designing and leading novel interventional trials focused on improving outcomes while reducing treatment burden and late effects for AYAs
- Performing focused, responsive outcomes research to identify and fill gaps for AYAs across the care continuum
- Advocating for AYAs through community outreach and promotion locally and remotely
- Interdisciplinary collaboration delivering the most effective care which seeks to address all of the needs of AYAs

University of Chicago AYA Oncology Program



Tara Henderson, MD, MPH
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Interim Chief, Section of
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Jennifer McNeer, MD, MS
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University of Chicago AYA Oncology Program



Denisse Martinez, LSW
AYA Program
Administrator



Renee Gracey, BSN, RN
AYA Oncology
Nurse Navigator



Amy Siston, PhD
Clinical Associate of
Psychiatry



Tina Drossos, PhD
Associate Professor of
Psychiatry

All of our nurses, schedulers, and support staff

AYA Oncology Program – Consult service

- Goals of Visits:
 - Provide fertility preservation counselling and connect with subspecialists as needed
 - AYA specific anticipatory guidance
 - Psychosocial needs assessment and support
 - Increase access to AYA Oncology Program's resources and research opportunities
 - Toxicity follow up / supportive care / survivorship monitoring

AYA Oncology Program – Consult service

- Consult visits:
 - At time of diagnosis
 - End of therapy
 - Relapse / survivorship / as needed

UofC AYA Oncology Program Research

- Clinical Trials
- Psychosocial research

UofC AYA Oncology Psychosocial Research

- Quantitative Measure:

DURING TREATMENT							
I need to be able to:		No	Need	Low Need	Moderate Need	High Need	Very High Need
40	spend time with people my own age	<input type="radio"/>					
41	talk to people my age who had been through a similar experience	<input type="radio"/>					
42	Attend some of my cancer care appointment remotely/virtually using telehealth options	<input type="radio"/>					
43	Information about sexual health and activity during treatment	<input type="radio"/>					



UofC AYA Oncology Psychosocial Research

• Sexual and Gender Minorities:

Section 2: Sexuality and gender identity: Next, I'd like to talk about sexuality and gender identity.

1. Sexual orientation: Can you tell me about how your oncologist relates to you in terms of your sexual orientation?
 - a. **Probe**: How do your interactions with your oncologist make you feel regarding your sexual orientation?
 - b. **Probe**: Did you disclose to or discuss with your oncologist your sexual orientation? Why or why not?



UofC AYA Oncology Psychosocial Research

- Qualitative Research:

- Aim 1: Amplify patient and caregiver voices in clinical and translational research
- Aim 2: Develop, evaluate, and improve mechanisms for disseminating health experiences research for use by CTSA researchers and stakeholders.
- Aim 3: Build infrastructure and capacity



Erika Cottrell
PhD, MPP

UofC AYA Oncology Psychosocial Research

- Enroll 50-60 patients
- Diagnosed with cancer 18-39
- 0-3 years post treatment – this is flexible

UofC AYA Oncology Psychosocial Research

12. The next few questions are going to be about how cancer could have impacted your body image, relationships, and sexuality:
 - a. Please describe how cancer and undergoing cancer treatment has had an impact on your body and how you view your body?
 - b. Sexual health is a really big topic that encompasses a lot of different things and can be hard to talk about at times. Some things like using contraception or protecting yourself from sexually transmitted infections are addressed. What were some of the things you remember hearing from your medical team about this? Were there things that weren't addressed that you wished would have been?
 - c. Did you feel you could talk about issues like sex or sexual health with your doctor? Were you able to discuss sensitive issues with others on your medical team?
 - d. I am wondering how treatment and being a cancer survivor has impacted your experience around dating and sex. Were you dating or sexually active prior to your cancer diagnosis?
 - i. If yes, how do you feel cancer and its therapy impacted your ability to date or impacted your ability to form the relationships you desired?
 - ii. If yes, did cancer and its therapy change your sexual relationships? Did you have any problems with sexual activity that was not present before (could give examples, such as pain with sex, difficulty with erections, change in pleasure)? How do you think cancer and its therapy impacted your sexual development? Did it impact how you defined sex?
 - iii. If no, was this something you desired and how do you feel cancer and its therapy impacted your ability to pursue it? How do you think your sexual development was impacted?

Conclusions

- AYAs with cancer have decreased improvement in APC of survival
- AYAs have unique needs and suffer from long term deficits in many psychosocial domains
- Much is not known yet about how best to address these needs

Future Directions

- Collaborative group studies specifically directed to AYA population
 - S1826 – SWOG / COG for advanced Hodgkin
 - COG with adult groups for early stage Hodgkin
 - SWOG and COG T cell ALL studies
- Determine effective interventions and when they should be offered