



AT THE FOREFRONT

UChicago
Medicine

Sexual Health in the AYA Population

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Disclosures and conflicts of interest

Disclosure: Jazz Pharmaceuticals – advisory boards; CE Concepts – speaker

Conflicts of interest: None

Outline

What is sexuality and why is it important?

What do our patients think of it?

What is the experience of patients undergoing active cancer therapy?

What is the experience of survivors?

How can we study it further?

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

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



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

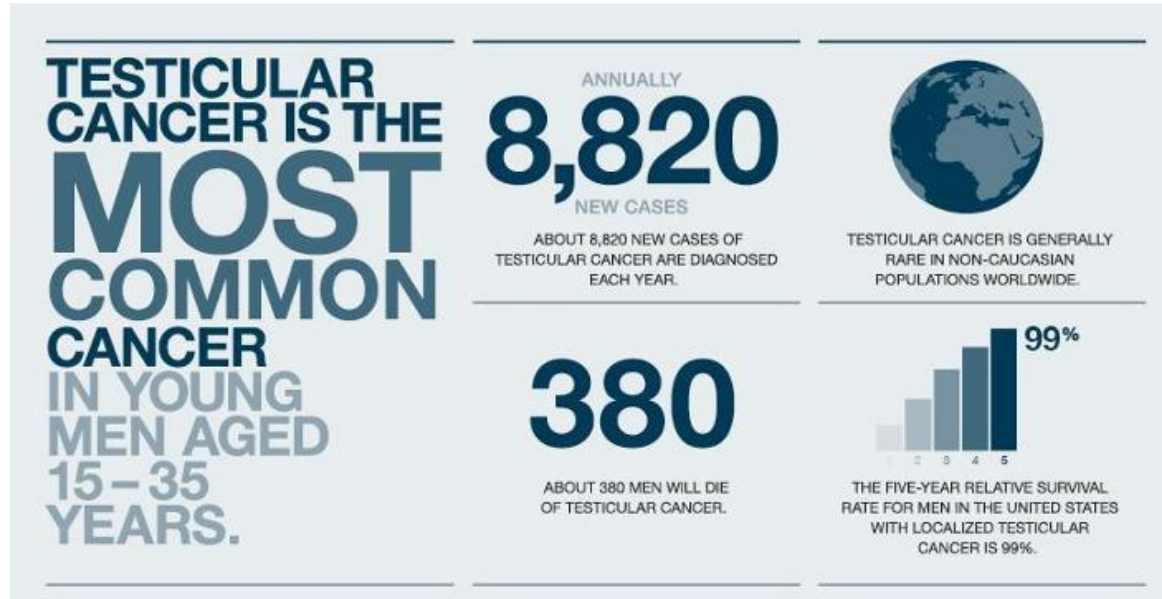
Not confident enough to engage in relationships

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

AYAs on active therapy



Survivors of AYA cancer

Fewer sexual experiences

High anxiety regarding sexuality

Increased risk-taking behavior

- Negative body image
- Missed experiences
- Peer influence
- Lower QoL

Less likely to initiate discussion with medical provider



Survivors of AYA cancer

Difficulties with disclosure of cancer

Cohabitation and marriage rates lower than age-matched controls

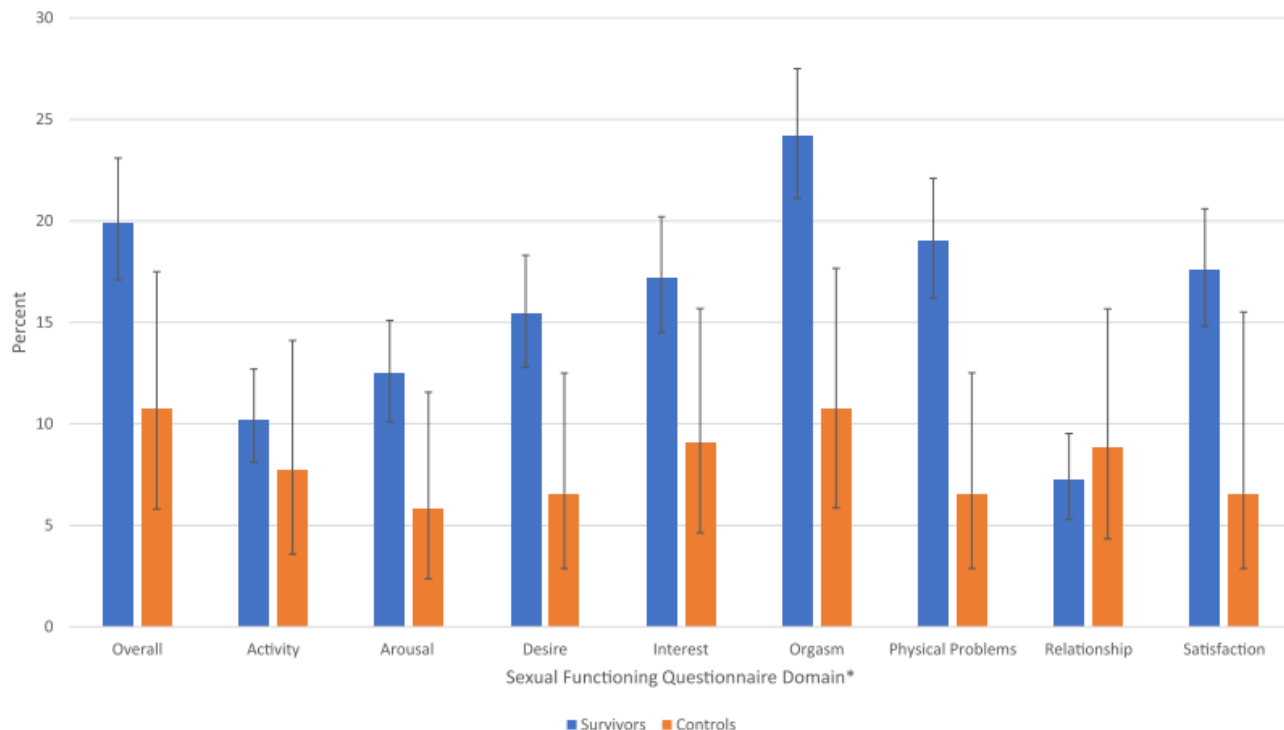
Stable employment lower than age-matched controls

Sexual Dysfunction in Childhood Cancer Survivors

Incidence: 20-50%

Nearly all types of sexual dysfunction reported

SD cannot be explained by specific treatment exposures alone (multidimensional)



Current Status of Sexual Healthcare in AYAO

- SH issues are widely under-recognized and under-treated across cancer types
- No data has been collected prospectively in trials
- No current knowledge about when deficits are developed
- No clear direction on when to time interventions

THEREFORE: Prospective sexual health evaluation is needed. Patient reported outcomes are an ideal approach.

Aims of Sexual Health PRO Battery:

- 1) Collection of descriptive information about sexual health, including sexual behaviors, function, body image, and relationships
- 2) Evaluate these outcomes longitudinally
- 3) Prospectively compare sexual health outcomes between groups and/or treatments.

Sexual Health Task Force

Member	Discipline
Natasha Frederick, MD, MPH Chair	Pediatric Oncology
Brooke Cherven, PhD, MPH, RN Vice Chair	Nursing
David R. Freyer, DO, MS	Pediatric Oncology
Jennifer Levine, MD	Pediatric Oncology
Jenna Demedis, MD, MS	Pediatric Oncology
Jessica Sheth Bhutada, MD	Pediatric Oncology
Adam DuVall, MD, MPH	Med-Peds Oncology
Gwendolyn Quinn, PhD	Psychology
Sharon Bober, PhD	Psychology
Kristen Bingen, PhD	Psychology

SH PRO Battery Overview

Development

- COG SHTF developed using a modified Delphi approach
- Followed approach taken by NCTN AYA PRO Task Force
- Incorporated feedback from NCTN AYA PRO Task Force

Concepts

- Sexual behaviors and needs
- Sexual function, body image, and relationships
- Sexual healthcare needs

Battery includes:

- Recommendations for inclusion
- Recommended populations and disciplines
- PRO items with outcome of interest, relevant timepoints for use, and details on origination of item (e.g. “modified from X PRO”)
- Example Objectives/Endpoints

Concept	Item	Outcome	Relevant Timepoints	Notes
Sexual Activity	(SH1) Before you were diagnosed with cancer, had you ever had any type of sexual activity? (Examples of sexual activity are masturbation, genital touching, oral sex, vaginal or anal penetration) (Y/N/Prefer not to answer)	Prevalence of AYA who were ever sexually active with/without a partner prior to diagnosis (N, %)	Baseline	Modified PROMIS item (added “vaginal or anal”, changed timeline to before diagnosis)
	(SH2) In the past 30 days, did you have any type of sexual activity? (Examples of sexual activity are masturbation, genital touching, oral sex, vaginal or anal penetration) (Y/N/Prefer not to answer)	Prevalence of AYA who are currently sexually active with/without a partner (N, %)	Baseline During treatment End of treatment Survivorship	Modified PROMIS item (added “vaginal or anal”)



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Sexual function

(SH3) Before you became sick, had you ever experienced any of the following? Check all that apply.

- You had no interest in sex
- You had erection difficulties
- Your vagina felt too dry
- You had pain during or after sex
- You had difficulty having an orgasm
- You felt anxious about having sex
- Some other sexual problem or concern
- No sexual problems/concerns

Or

Prefer not to answer (cannot check this with others)

Prevalence of sexual function concerns prior to diagnosis (N, %)

Baseline

Modified from Single Item Screener - Flynn J Gen Int Med 2015 (removed “sexual problems or concerns” from question stem and added “sexual” to last two response choices)

(SH4) In the past 30 days, have you experienced any of the following? Check all that apply.

- You had no interest in sex
- You had erection difficulties
- Your vagina felt too dry
- You had pain during or after sex
- You had difficulty having an orgasm
- You felt anxious about having sex
- Some other sexual problem or concern
- No sexual problems/concerns

Or

Prefer not to answer (cannot check this with others)

Prevalence of current sexual function concerns (N, %)

Baseline
During treatment
End of treatment
Survivorship

Modified from Single Item Screener - Flynn J Gen Int Med 2015 (removed “sexual problems or concerns” from question stem and added “sexual” to last two response choices)

(SH5) In the past 30 days, how distressed or bothered have you been by changes in sexual function? (Not at all, a little, quite a bit, very much, prefer not to answer)

Rating of patient distress about sexual function

Baseline
During treatment
End of treatment
Survivorship

Derived from General Symptom Distress Scale (Badger 2011)



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Sexual or romantic relationships	(SH6) Are you currently involved in a sexual or romantic relationship? (Y/N/Prefer not to answer)	Prevalence of current sexual and/or romantic relationship (N, %)	Baseline During treatment End of treatment Survivorship	Add Health survey
	BRANCHING (SH6=N) (SH6a) (In the past 30 days, how worried or concerned have you been about dating or trying to start romantic or sexual relationships? (Not at all, a little, quite a bit, very much, prefer not to answer)	Rating of patient worry about dating/romantic relationships	Baseline During treatment End of treatment Survivorship	Derived from existing qualitative data
	BRANCHING (SH6=Y) (SHb) (In the past 30 days, how worried or concerned have you been about your romantic or sexual relationship(s)? (Not at all, a little, quite a bit, very much, prefer not to answer)	Rating of patient worry about dating/romantic relationships	Baseline During treatment End of treatment Survivorship	Derived from existing qualitative data

Body/Self Image	(SH7) In the past 30 days, have you been feeling that cancer or your treatment has left your body less whole or “damaged”? (Not at all, a little, quite a bit, very much, prefer not to answer)	Rating of effect of cancer/treatment on body	Baseline During treatment End of treatment Survivorship	Derived from Hopwood Body Image Scale Q8 (added 30 day limit)
	(SH8) In the past 30 days, have you avoided romantic relationships or sexual experiences because of the way you feel about your appearance? (Not at all, a little, quite a bit, very much, prefer not to answer)	Rating of effect of body image on relationships/sexual experiences	Baseline During treatment End of treatment Survivorship	Derived from Hopwood Body Image Scale Q7 (added 30 day limit; changed “avoid people” to “avoid relationships or sexual experiences”)

Sexual healthcare needs	<p>(SH9) Which of the following topics would you like your oncology team to address? Check all that apply.</p> <p>Safe sexual behaviors when blood counts are low</p> <p>Preventing sexually transmitted infections</p> <p>Contraception (birth control)</p> <p>Dating and Romantic relationships</p> <p>Sexual problems</p> <p>Sexual orientation</p> <p>Gender Identity</p>	Prevalence of unmet sexual health needs (N, %)	<p>Baseline</p> <p>During treatment</p> <p>End of treatment</p> <p>Survivorship</p>	Derived from existing qualitative data
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Project Structure

Patient Advisory Council (Co-Chairs: Lopez & Ghazal)

Include an additional 10 SGM and Racial/Ethnic minority AYAs (one from each partner)

Project Home Base

Project Co-Leads

Anao Zhang & Lauren Ghazal

Senior Advisor

Bradley Zebrack

Project Consultants

Christabel Cheung & Nina Jackson Levin

Project Coordinator

Cinthia Villarreal

Academic & Community Partners

Columbia: Beauchemin

MD Anderson: Griffith, Roth, & Acquati

UChicago: DuVall & Mehrtens

UMich: Walling

USC: Li & Kuperberg

Elephants & Tea: Giallourakis

GRYT Health: Lastauskas

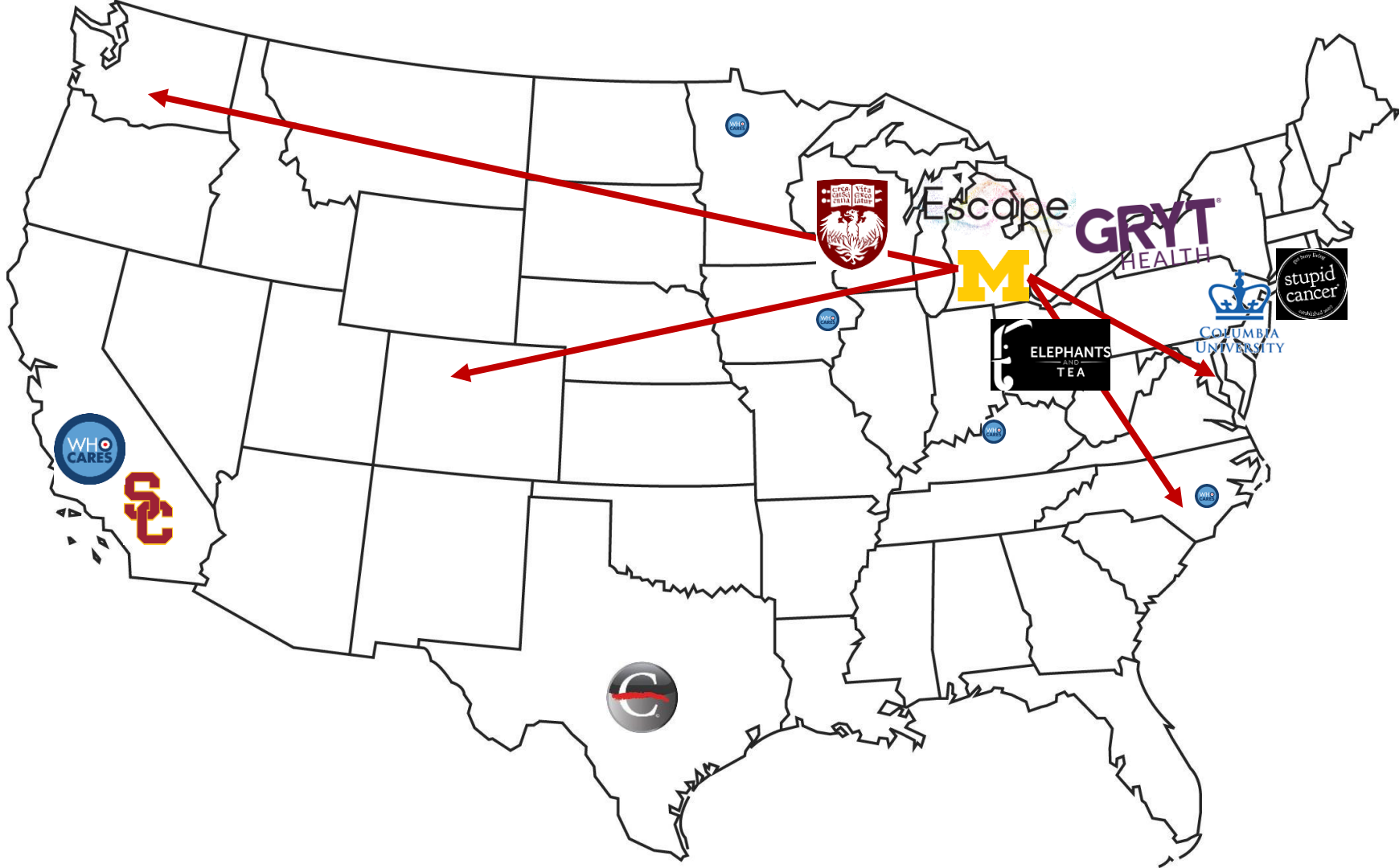
Escape: Johnston, Ramachandra, &
Dodd

Stupid Cancer: Donahue

Teen Cancer America: Gan



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Projected Outcomes and Outputs:

Short-term outcomes during the project period include **a white paper** summarizing stakeholder-suggested strategies and practices to engage BIPOC and SGM AYA cancer survivors in PCOR/CER.

Medium-term outcomes (zero-two years post-project period) include continued connections and collaborations between all participating academic and community partners with AYA CaRES, focusing on efforts engaging BIPOC and SGM AYAs.

Long-term outcomes (three or more years post-project period) include the continued growth of AYA CaRES at the University of Michigan by establishing **a national consortium of AYA cancer research**.

Conclusions / Future Directions

- Sexual health is a broad subject area that is vital to AYAs with cancer
- SH is understudied and requires further evaluation
- AYAs with cancer clearly have long-term deficits in the many SH domains
- Future work is already being done to shed a light on this important subject



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AYA Nurses, Patients, and Families