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Sexual Health in Adolescent and Young Adult Oncology Patients

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Annual Meeting on Supportive Care in Cancer

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Sexual Health In Adolescent and Young Adult Oncology Patients

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June 21st, 2019

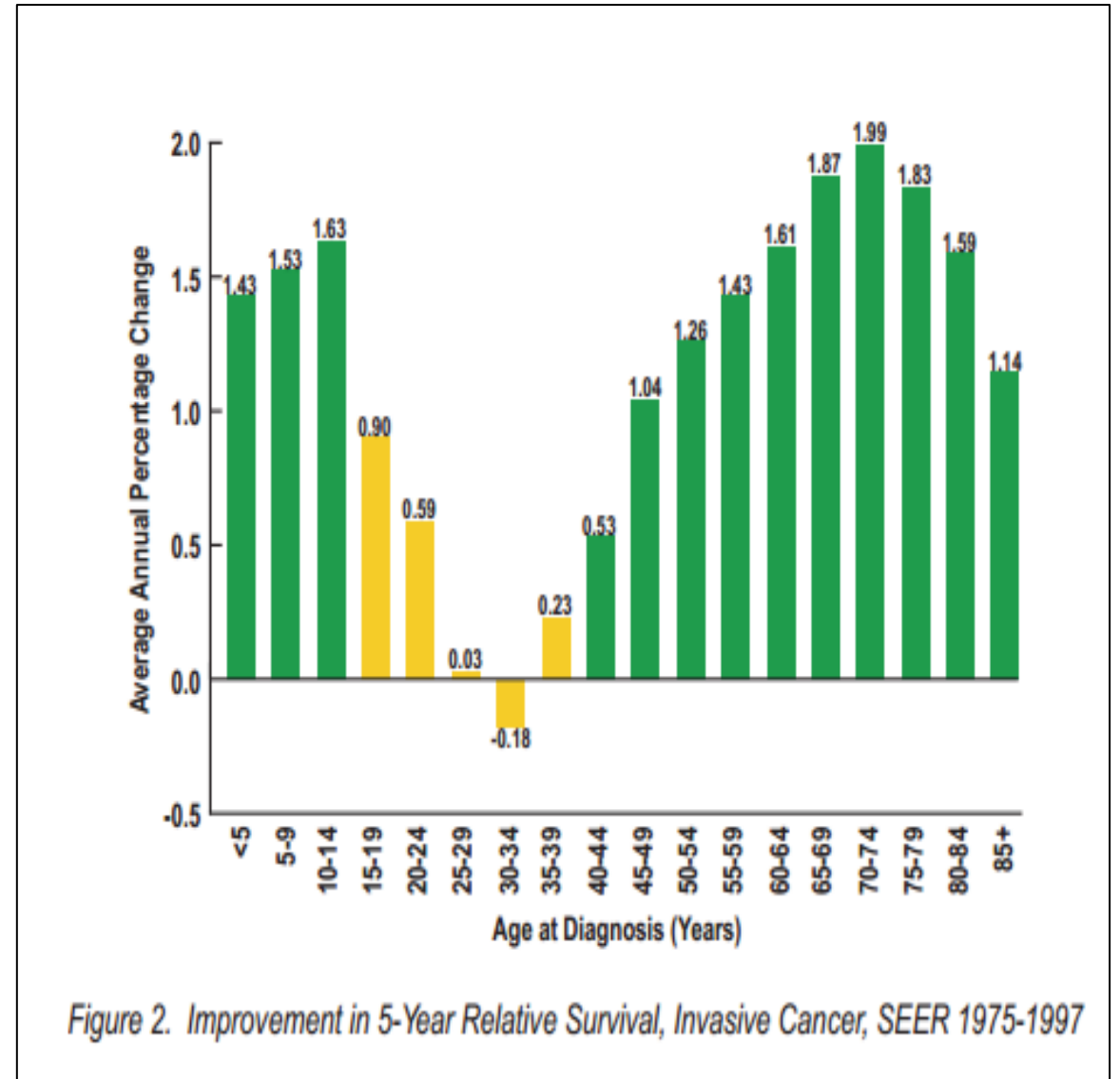


- I have no disclosures



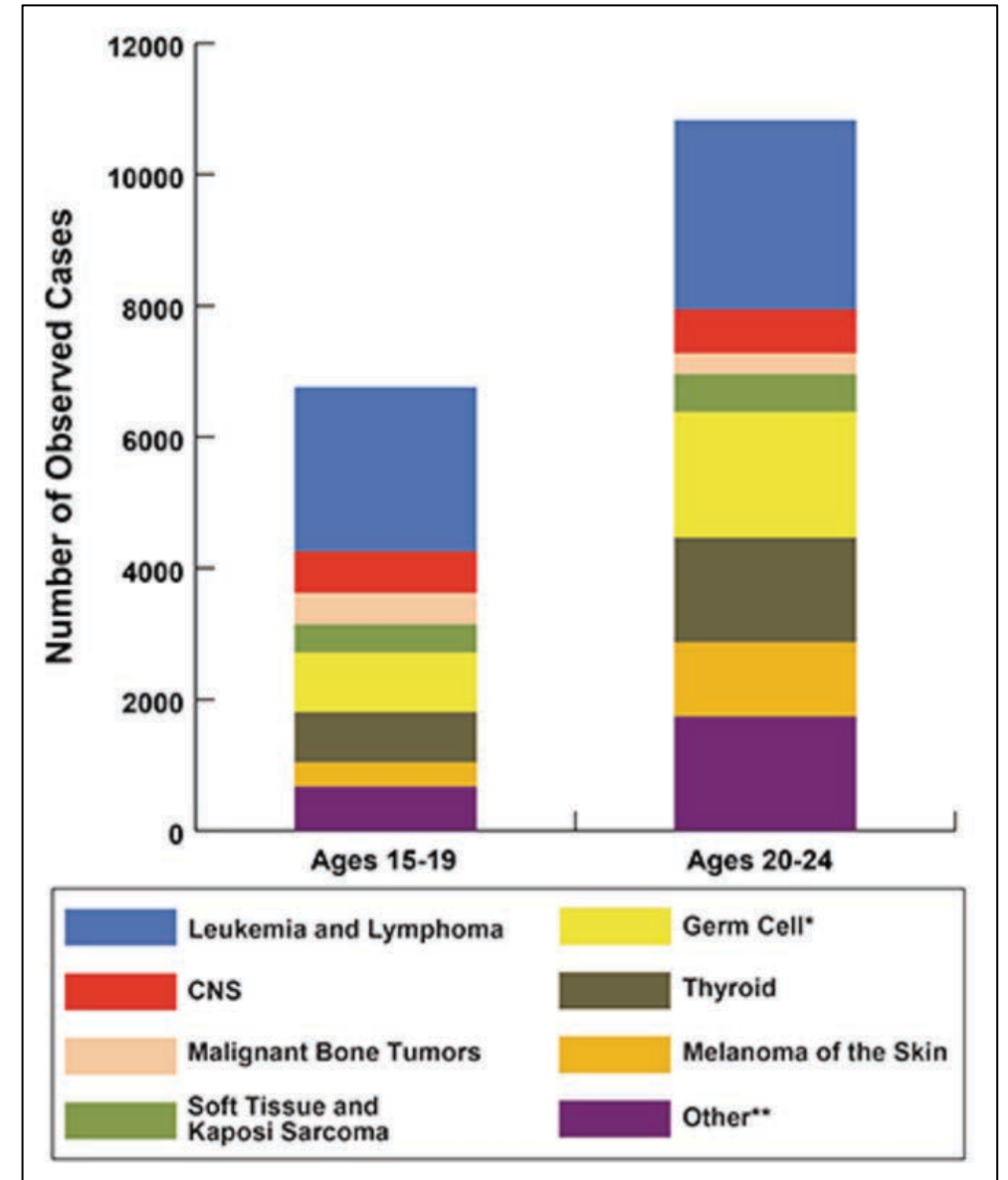
AYA Oncology

- Nearly 70,000 AYAs are diagnosed with cancer in the US each year (ages 15-39 years)
 - About 7% of total new diagnoses in the US
- Improvements in survival rates and quality of life (QOL) outcomes lag behind those of children and older adults



AYA Oncology

- **Why?**
 - Tumor and host biology
 - Treatment response
 - Poor participation in clinical trials
 - Developmental and life stage differences
 - Distinct psychosocial needs



Adolescent Development

- Identity
 - Sexual identity
- Body image
- Intimate and emotional relationships
- Sexual and Reproductive Health
 - Sexual function
 - Contraception
 - Fertility
- Separation from parents
- Independent decision making about future goals



Sex and AYAs

- Healthy AYAs engage in risky health behaviors, including risky sexual health behaviors, as part of normal development.
- Nearly half (46.8%) of high school students in the United States had ever had sexual intercourse, with only 59.1% reporting condom use during their last sexual intercourse.
- Adolescents with *chronic disease* are at increased risk for engaging in risky behaviors compared to age-matched peers.

Sex and AYAs with cancer

- Adolescent *survivors* of early childhood cancer engage in risky behaviors, including sexual behaviors, at rates equivalent to controls.
- AYAs remain sexually active *during* cancer treatment.
- AYAs with cancer use contraception less often than their healthy peers.

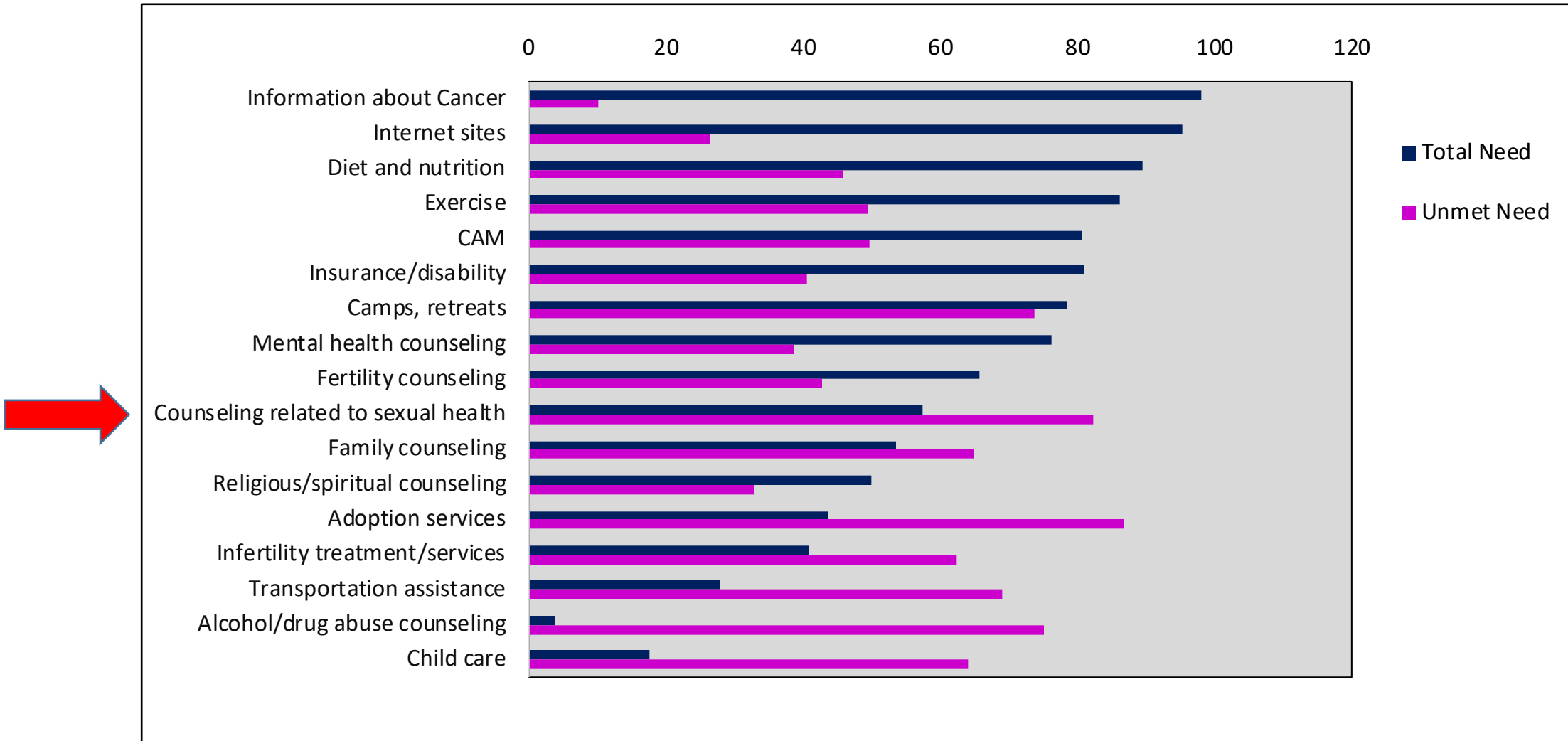
	At diagnosis (n/total)	3-6 mo. later (n/total)
Currently dating	38% (13/34)	35% (8/23)
Currently sexually active	26% (9/35)	32% (7/22)
Ever had sex	26% (9/35)	59% (13/22)
Use birth control/condoms	44% (4/9)	29% (2/7)

Rosenberg J Adol Health 2016

Sex and AYAs with Cancer

- AYAs consistently indicate the need for improved communication on sexual and reproductive health (SRH) issues.
- Oncology providers often underestimate the relevance of psychosexual issues among AYA patients with cancer.
 - Forget to include SRH conversations as part of ongoing assessments through disease treatment and survivorship.
- AYAs are generally uncomfortable initiating conversations.

AYAs have unique unmet needs



Medical team
assumptions
Inadequate
anticipatory
guidance

Hormonal changes
Structural damage
Disfigurement
Pain, Fatigue
Fertility

**Biologic/
Physical**

Knowledge

Psychological

Depression
Anxiety
Body image
Negative thinking
Self-efficacy

**AYA
Problems
with Sexual
Health**

Developmental

Age at diagnosis
Autonomy
Independent
decision
making
Identity
development

**Social/
Cultural**

Social norms
Cultural norms
Peer networks
Religious beliefs

Interpersonal

Fear of intimacy
Lack of communication

What do AYA patients say?

AYAs do not discuss sexual health with oncology providers

*No, they just wanted to make sure I got my period and grew some boobs.
They never talked about sex at all.*

*I think he'd asked me if I was having sex and if I used protection and I'd say
yes, but I never talked more in depth about it.*

What do AYA patients say?

AYAs want to talk about sexual health

It's something that's normal...it should be talked about and spoken about like any other healthy body issues.

I kind of wish she brought it up to say like, "hey, this could be related to your cancer treatment...If you want to talk about it we can." I kind of never knew if it was in the realm of things I was allowed to talk about to her.

Why do AYAs want SRH information from oncology clinicians?

- **General education**

“Because [teens] have all these different issues with going through chemotherapy and may have different questions which may not be covered in class.”

- **SRH issues during cancer treatment**

“I struggled with sexual health questions through my treatment...I think that just overall more education would have put me, maybe caused a little less stress in my life.”

- **Knowledge of potential late effects**

“I think it’s important to know what’s going on and how cancer is going to affect me in the future. I’d just rather know everything that might affect me.”

Sexual function impacts QOL

- Sexual health and fertility are deemed “Most Important” by AYAs
- About 30% AYAs in survivorship report problems with sexual function
- 20% report sexual limitations due to cancer
- Sexual dysfunction does not “improve with time”
 - >50% report ongoing problems with sexual function 2 years out from diagnosis

Clinician-reported barriers

- Semi-structured interviews with 22 oncology clinicians across 7 pediatric academic institutions.
- All recognized the importance of talking about SRH issues but struggled with these conversations.

Barrier	N (%)
Lack of resources	17 (77%)
Clinician discomfort	16 (73%)
Low priority	16 (73%)
Presence of parents/family	16 (73%)
Lack of knowledge	14 (64%)
Time	12 (55%)
Perceived patient discomfort	11 (50%)
Lack of rapport	7 (32%)

Talking to AYAs about Sexual Health

How do AYAs want this information?

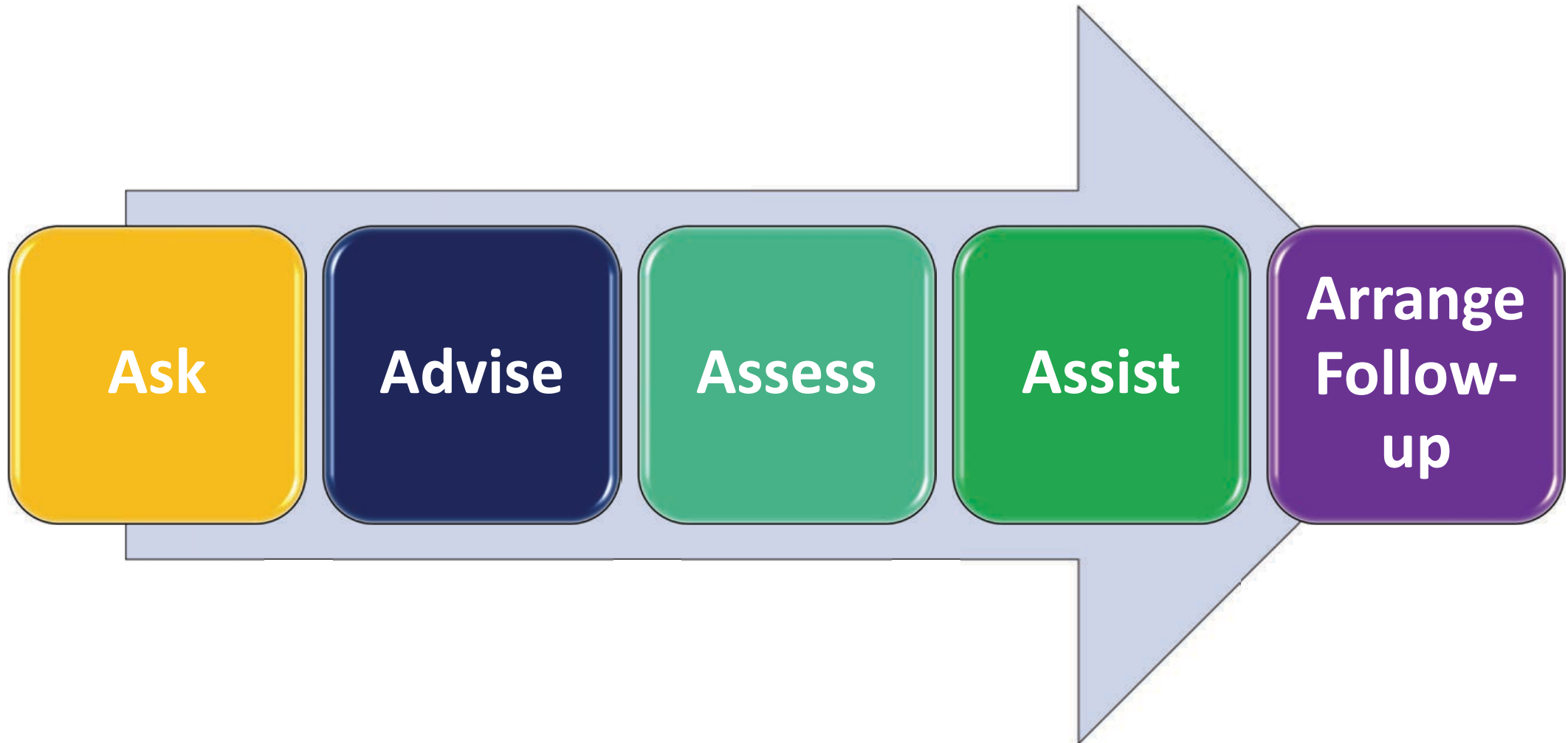
- Direct communication from clinician
- Clinician to initiate
- Ongoing conversation
- Provide time alone with the clinician
- Normalize the conversation
- Individualize

How do we start the conversation?

- Create a safe and appropriate environment
- Respect confidentiality
- Individualize conversations
- **Don't make assumptions!!!**



Communication Framework: The 5 As



Ask

- Introduce the topic of sexual health and ask the patient for permission to proceed with the conversation

“Many AYAs worry about how cancer will affect dating and relationships. I would like to take some time today to talk about this. Is this okay with you?”



Advise

- Provide a brief overview on a specific sexual health topic.
“While sexual and romantic relationships may still continue or develop during cancer therapy, there are a few things that are important for you to know.”
- Depending on patient need, consider discussing the following:
 - Puberty/development
 - Contraception
 - Safe sex practices
 - Sexual function



Assess

- Ask additional questions to understand patient education and support needs

“The following questions are personal, however I ask them so that I may have the best understanding of your current health and to provide you with information that you need to keep yourself as healthy as possible through treatment.”

Assist

- Provide brief counseling based on conversation/assessment.
- Give appropriate handouts, pamphlets, website links, etc.
- Make referrals as necessary
 - Urology
 - OB/GYN
 - Reproductive endocrinology
 - Adolescent medicine
 - Psychology

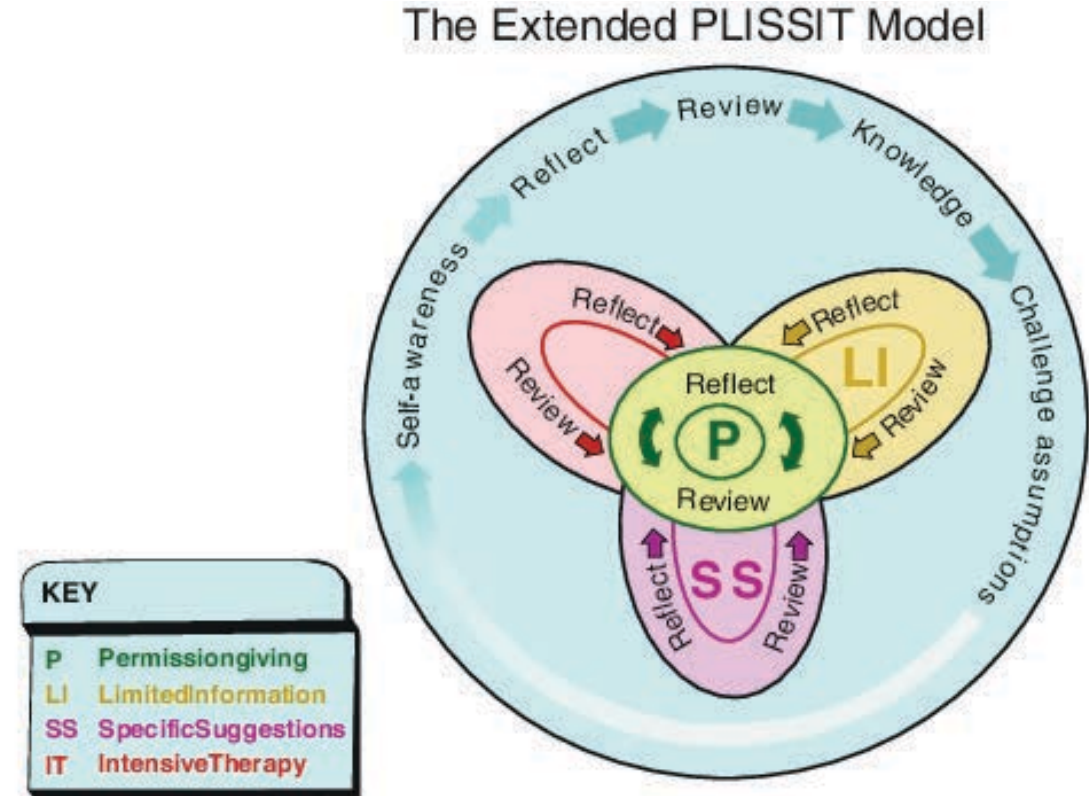
Arrange follow-up

- Schedule a follow-up visit to review identified problems or concerns.
 - Initiate the conversation!



Extended PLISSIT

- Permission
- Limited Information
- Specific Suggestions
- Intensive Therapy



Additional Resources

- National Coalition for Sexual Health
<https://nationalcoalitionforsexualhealth.org/>
- Physicians for Reproductive Health
<https://prh.org/medical-education/>

Summary

- AYAs want oncology clinicians to discuss SRH throughout cancer care
- AYA recommendations for clinicians:
 - Initiate the conversation
 - Offer time alone
 - Normalize
 - Engage in ongoing conversation
 - Individualize
 - Directly communicate with AYA
- Adopt an approach to sexual health conversations that works best for you. **The most important step you can take is to ask!!!**

Thank you!

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