ECHO Workshop

Gwendolyn Quinn, PhD

Susan Vadaparampil, PhD, MPH

Agenda

Time	Session/Activity
9:00-9:30 (STV & GQ)	Introductions and Workshop Overview
9:30-10:00 (STV)	Communication Strategy 1: 3 Key Time Points to Discuss Fertility Preservation
10:00-10:30 (STV)	Activity 1: Discuss Barriers and Facilitators to Discussing Fertility Preservation at Key Time Points
10:30-11:00 (GQ)	Communication Strategy 2: Discussing Fertility Preservation with Adolescent Patients and their Parents
11:00-11:30 (GQ)	Activity 2: Values Clarification Tool
11:30-12:00 (GQ)	Communication Strategy 3: Discussing Risk of Infertility and Fertility Preservation with a Patient/Survivor and Partner/Support Person
12:00-12:30 (GQ)	Activity 3: Case study with Standardized Patient (Josie)
12:30-1:30	Lunch
1:30-2:00 (STV)	Communication Strategy 4: Discussing Sexual Health
2:00-2:30 (STV)	Activity 4: Video Vignettes Discussion
2:30-3:00 (STV & GQ)	Wrap-Up and Discussion

What is ECHO?

- ECHO (**E**nriching **C**ommunication Skills for **H**ealth Professionals in **O**ncofertility)
- Web-based training program that includes psychosocial, biological, clinical and skill building modules to help allied health professionals communicate timely and relevant information regarding reproductive health to their adolescent and young adult (AYA) patients
- Why participate?
  - 17.75 FREE continuing education credits
  - Free educational materials
  - Training facilitated by a national team of experts
  - Certificate of completion

Apply Today!

- Interested learners should submit their application on our website at http://echo.rhoinstitute.org/2020-echo-application/
- Deadline to apply is November 22, 2019
- Course runs January – March
- For additional information or questions, please contact us:
  - Phone: (813) 745-6213
  - Email: ECHO@Moffitt.org
  - Website: www.echo.rhoinstitute.org

Learning Objectives

- List 3 key time points to discuss fertility preservation
- Identify strategies for discussing fertility preservation with adolescent patients and their parents
- List all components of the AIDED model for discussing fertility preservation with survivors and their partner and/or support person
- List all components of the BLISSS model for discussing sexual health

Communication Strategy 1

3 Key Time Points to Discuss Fertility Preservation

Communication: A Multistep Process

Communication at 3 key time points with multiple stakeholders

1) Speak with the **oncologist** and **other members of the health care team** involved in treatment

2) Speak with the **patient** before treatment begins

3) After the discussion with the patient, follow up with:

The Patient: written communication to summarize discussion/options

Other Health care professionals: coordinate for patients who request additional information or services

Conversations should be on-going across the cancer care continuum including survivorship care.

1) Before the Discussion

Communication Before Discussing Fertility with the Patient

- Clarify with the health care team involved in treatment:
  - Is there a risk of infertility from the planned treatment?
  - Is there time available to pursue fertility preservation?
  - What are the fertility preservation options?
- Consider the following information:
  - Are there any special considerations, for example does the patient have a hormone-sensitive tumor?
  - Are there any medical contraindications to pursuing fertility preservation?

Before the Discussion: Treatment & Infertility Risk?

Susan

- ACT Regimen
  - Cyclophosphamide destroys eggs
- Tamoxifen
  - At least 5 years--10 year recommendation
  - Known to cause birth defects
  - Patients should not get pregnant while taking it
- Age
  - Natural decline in reproductive capacity

Before the Discussion: Time for Fertility Preservation Options?

Is there time to pursue fertility preservation before chemotherapy?

Egg/Embryo Freezing

Surgery → ~6 Weeks → Chemotherapy

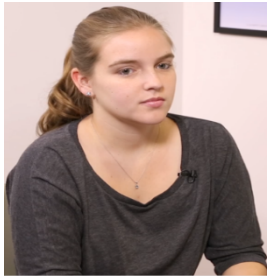
Process takes 2-1/2 to 3 weeks

REI consultation

Egg retrieval

Day 2 of menses hormonal stimulation begins (takes ~10 days)

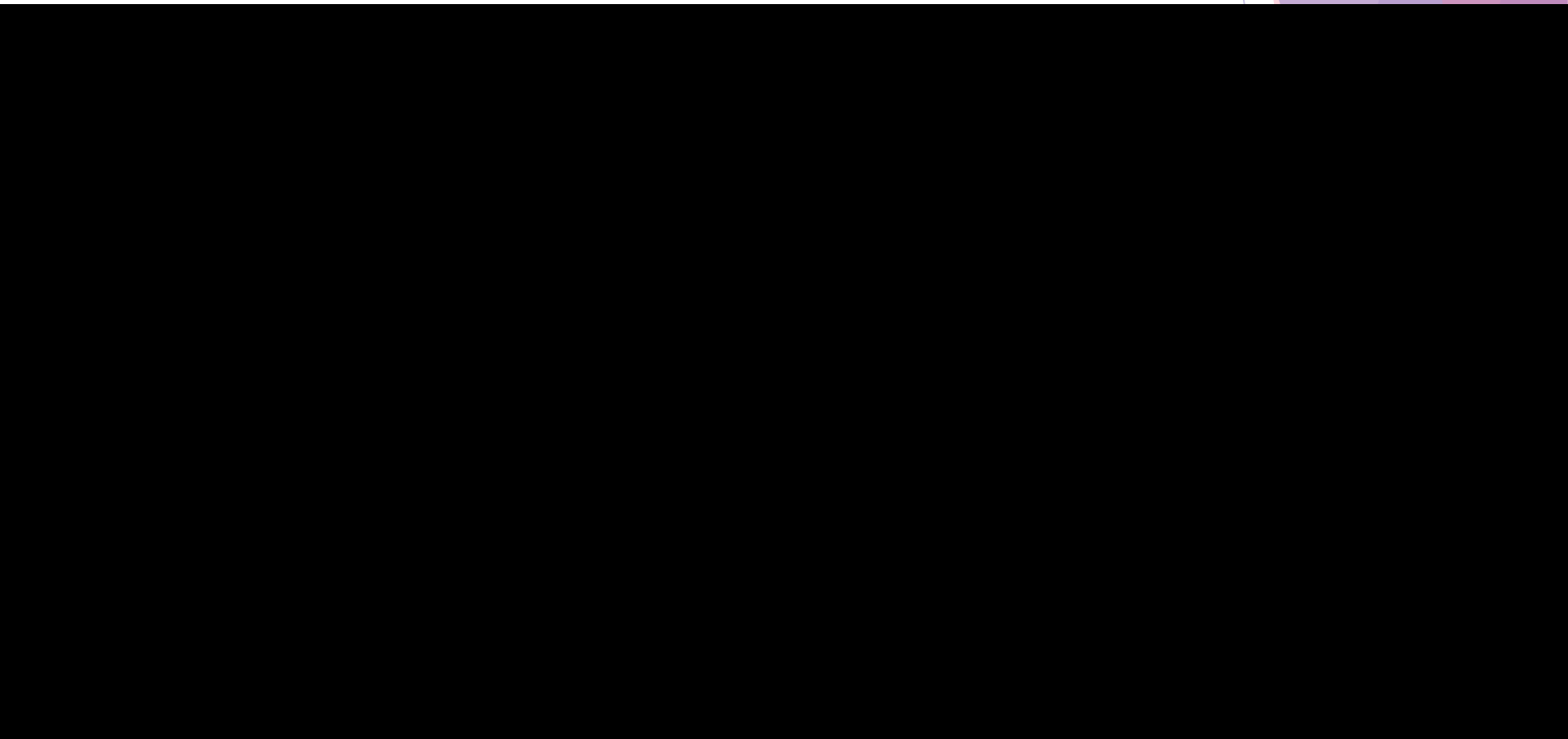
Information established prior to discussion with the Patient



- ✓ Therapy puts increased risk for fertility issues
- ✓ Adequate time to pursue fertility preservation
- ✓ No contraindications

2) During the Discussion

Starting the Discussion: Communicating Fertility Risk to Susan



During the Discussion: Communicating Fertility Risk to Susan

During the Discussion: Communicating Fertility Risk

- Recognize the difficulty in processing this information:
  - Allow the patient to ask questions
  - Preview the main points that will be covered
  - Communicate uncertainty

During the Discussion: Communicating Fertility Preservation Options

During the Discussion: Communicating Fertility Preservation Options

During the Discussion: Communicating Fertility Preservation Options

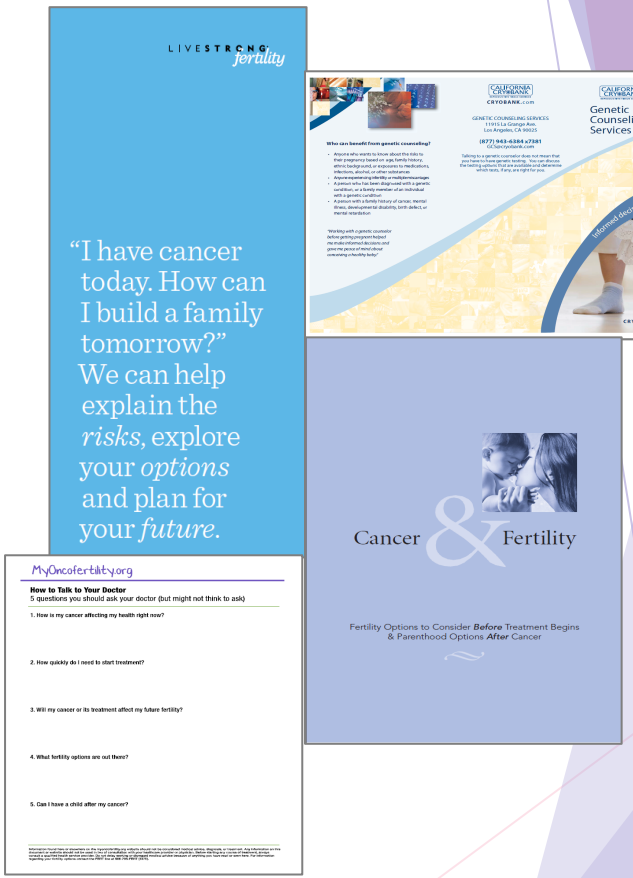
- Support the patient and ensure understanding
- Reassure the patient
- Ask the patient what questions they have
- Provide the patient with options they may consider:
  - Reassure patient that if they choose not to undergo fertility preservation and become infertile in the future, there are other options for them to have a child, such as using a donor egg or adoption
- Present the reproductive endocrinologist as a resource or another member of their care team

3) After the discussion

Communicating After the Discussion: Patients

Provide the Patient With:

- Your contact information in case they have additional questions or want you to help with a referral
- Written information to reinforce what you have explained
- List of resources for the patient to learn more
  - A list of sperm banks
  - A list of local REIs
  - Informational Websites
  - Support Organizations



Fertile Hope Patient Resource: http://www.livestrong.org/we-can-help/fertility-services/
Cryobank Resource: http://www.cryobank.com/_resources/pdf/Brochures/Genetic-Counseling-Services-Brochure.pdf
Cleveland Clinic Resource: http://my.clevelandclinic.org/Documents/OB_GYN/FertileHope.pdf
MyOncoFertility Resource: http://www.myoncofertility.org/sites/myoncofertility.org/files/Patients%20Questions_0.pdf

Communicating After the Discussion: Other Team Members

- Local REI's
- Financial counselors
- Patient navigators
- Other health professionals
  - Nurses
  - Physician Assistants
  - Psychologists
  - Social workers
  - Genetic counselors
- Follow up with the referring oncologist to tell them of patient's decision and the plan

Activity 1: Discuss Barriers and Facilitators

- Split into groups of 5
- 15 minute group discussion
- 15 minutes for groups to present

Activity 1: Discuss Barriers and Facilitators

- Take turns introducing yourself:
  - Name
  - Type of Allied Health Professional (e.g., nurse, social worker)
  - Fun fact
- Appoint one individual to be your group's presenter
- Based on your profession, what are some barriers and facilitators to discussing fertility preservation at key time points?
  1. Before the discussion
  2. During the discussion
  3. After the discussion

Communication Strategy 2

Discussing Fertility Preservation with Adolescent Patients and their Parents

Case: Jake & Parents

Clinical History

- 15 year old male
  - Newly diagnosed with medulloblastoma
  - Post surgery, but will soon be treated with cranio-spinal irradiation and alkylating agents
  - Radiation therapy will begin in 3 days

Social history

- Lives at home with his parents (who are still married) and his sister
- Adopted
- Has a girlfriend of 6 months (sexually active)

Educational/occupational history

- Rising 10th grader at a public high school
- Works a part-time job as a life-guard (seasonally)

Discussion Strategy: Overview

- Designing clinical encounter into 4 discrete units:
  - 1) Family - Introduction, session rationale, and orientation to fertility preservation
  - 2) Patient only – Rapport building, desire for biological children, developmental readiness for banking, assessment of candidacy
  - 3) Parents only – Desires for son, personal perspectives, assessment of barriers or objections
  - 4) Family – Development of fertility preservation plan moving forward

Patient, Parents, and Psychologist (Initial Visit)

1) Initial Contact with Family

- Welcome, personal introduction, rationale for meeting
- Communication of goals for session
- Setting expectations for flexible decision-making (not two choices only - bank or no bank)
- Orientation to treatment, its effect on fertility, and fertility preservation options
    - Orientation to the structure of the session
    - Setting expectations for the sensitive nature of the discussion
    - Fertility preservation decision-making process and timing

Patient and Psychologist

Patient and Psychologist: Key Talking Points

- Desire of biological fatherhood (score 3-4, on a scale of 0-10)
- Reflective listening
- Use of humor
- Acknowledgement of the embarrassing/personal nature of impending interview
- Communication of rationale for sperm banking
    - Procedural demands and logistics associated with a collection attempt

Parents and Psychologist

Parents and Psychologist: Key Talking Points

- Parent perspectives and desires for Jake
- Correcting parent misperceptions
- Rationale for including Jake in the decision making process and managing decision fatigue

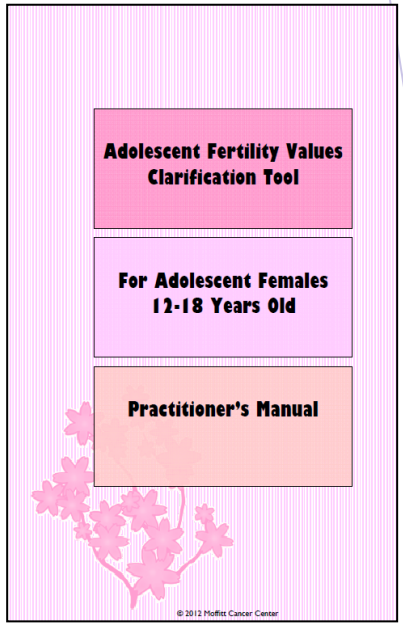
Patient, Parents, and Psychologist (final visit)

Patient, Parents and Psychologist

- Review of family discussion about sperm banking decision-making
- Summary of the family's decision to take more time in making the decision
- Providing brief information about heritable cancers and offering to make a referral to genetic counseling
- Hearing from all 3 family members about session outcome and plan moving forward
- Offering provider contact information should additional questions arise
- Follow-up in two weeks
- Provision of written materials
- Final wrap up

Activity 2: Adolescent Fertility Values Clarification Tool (AFVCT)

- Split into groups of 5
  - Again select a group presenter
- 15 minute group discussion
- 15 minutes for each team to present



Activity 2: Adolescent Fertility Values Clarification Tool (AFVCT)

1. How is the AFVCT different from other quality of life or values clarification tools?
   - What are the pros and cons of the AFVCT?
2. Why doesn't the AFVCT have a scoring system?
   - What are the pros and cons of no scoring system?
3. Can the AFVCT be administered by a parent, friend, or relative?
   - Who should administer the AFVCT?
   - How would you build rapport with your patient(s)?
4. What would you do if the patient cannot understand English?
5. Can the AFVCT be used for girls under age 12?
6. Can the AFVCT be used for adolescent boys?
   - How would you modify the existing AFVCT to be used for boys?

Communication Strategy 3

Discussing Risk of Infertility and Fertility Preservation with a Patient/Survivor and Partner/Support Person

AIDED Model

- **A**ssess patient's general understanding of their diagnosis and the potential impact on fertility as well as current and future desires for parenting
- **I**ntroduce the topic of fertility and why you are discussing this topic
- **D**escribe potential impact of a cancer diagnosis and/or treatment on fertility and available options to assess current fertility and future biological and non-biological parenting options
- **E**xplain the timeline for assessing fertility and pursuing future parenting options and refer to relevant specialists
- **D**iscuss and provide patients with information and offer support to facilitate decisions about fertility preservation

Female Patient Case: Miranda

Clinical History

- 23 years old
- Hispanic/Latino
- Diagnosis: Leiomyosarcoma (abdomen)
- Treated with chemotherapy
- First post-treatment visit
- No documentation about fertility or fertility preservation discussion in medical record

Social History

- Married, husband John
- No children, but hopes to have at least one
- Family (both immediate and in-laws) live close by
- Graduated with BA in Elementary Education
- Miranda employed as a 1st grade teacher
- John is 26, employed as an engineer

AIDED

- **A**ssess patient's general understanding of their diagnosis and the potential impact on fertility as well as current and future desires for parenting
- **I**ntroduce the topic of fertility and why you are discussing this topic
- **D**escribe potential impact of a cancer diagnosis and/or treatment on fertility and available options to assess current fertility and future biological and non-biological parenting options
- **E**xplain the timeline for assessing fertility and pursuing future parenting options and refer to relevant specialists
- **D**iscuss and provide patients with information and offer support to facilitate decisions about fertility preservation

AIDED

- **A**ssess patient's general understanding of their diagnosis and the potential impact on fertility as well as current and future desires for parenting
- **I**ntroduce the topic of fertility and why you are discussing this topic
- **D**escribe potential impact of a cancer diagnosis and/or treatment on fertility and available options to assess current fertility and future biological and non-biological parenting options
- **E**xplain the timeline for assessing fertility and pursuing future parenting options and refer to relevant specialists
- **D**iscuss and provide patients with information and offer support to facilitate decisions about fertility preservation

AIDED

- **A**ssess patient's general understanding of their diagnosis and the potential impact on fertility as well as current and future desires for parenting
- **I**ntroduce the topic of fertility and why you are discussing this topic
- **D**escribe potential impact of a cancer diagnosis and/or treatment on fertility and available options to assess current fertility and future biological and non-biological parenting options
- **E**xplain the timeline for assessing fertility and pursuing future parenting options and refer to relevant specialists
- **D**iscuss and provide patients with information and offer support to facilitate decisions about fertility preservation

AIDED

- **A**ssess patient's general understanding of their diagnosis and the potential impact on fertility as well as current and future desires for parenting
- **I**ntroduce the topic of fertility and why you are discussing this topic
- **D**escribe potential impact of a cancer diagnosis and/or treatment on fertility and available options to assess current fertility and future biological and non-biological parenting options
- **E**xplain the timeline for assessing fertility and pursuing future parenting options and refer to relevant specialists
- **D**iscuss and provide patients with information and offer support to facilitate decisions about fertility preservation

AIDED

- **A**ssess patient's general understanding of their diagnosis and the potential impact on fertility as well as current and future desires for parenting
- **I**ntroduce the topic of fertility and why you are discussing this topic
- **D**escribe potential impact of a cancer diagnosis and/or treatment on fertility and available options to assess current fertility and future biological and non-biological parenting options
- **E**xplain the timeline for assessing fertility and pursuing future parenting options and refer to relevant specialists
- **D**iscuss and provide patients with information and offer support to facilitate decisions about fertility preservation

Activity 3: Case Study-Josie

- Please watch the following live simulation of the interaction between a survivor (Josie), her companion support system (sister), and the provider (Dr. Sampson)
- Please be prepared to provide constructive feedback about the interaction:
  - Pros about the interaction
  - Areas of improvement
  - How could/would you approach it differently?

Activity 3: Case Study-Josie

Clinical History

- 28 years old, 23 at diagnosis
- Hispanic
- Ewing sarcoma (left leg)
- Treatment included: chemotherapy, resection surgery, and radiation at pediatric hospital under pediatric protocol
  - Very high alkylating agent poses threat to fertility
- Currently on treatment
- Was referred by physician at supportive care clinic because she mentioned distress related to current relationship and future family building
  - No documentation about fertility or fertility preservation discussion in medical record and patient reports not recalling discussion

Social History

- Social Long term relationship with male partner, living together, not married
- Graduated with a high school diploma
- Currently employed as a beautician
- Enrolled in a certification school paid for by her employer
- Partner is a Caucasian, Southern Baptist and comes from a big family and hopes to have at least 3 children
- Distress about infertility, uncertainty, and impact of this distress on partner
- Accompanied by her sister which is her only source of support outside of her partner

Communication Strategy 4

Discussing Sexual Health

Before the Conversation

- Assess your own comfort discussing sex with various patient groups and identify any biases that you may have. If you are uncomfortable talking about sex and sexuality, your patient will be too.
- Make your patient feel comfortable and establish rapport before asking sensitive questions.
- Use neutral and inclusive terms (e.g., “partner”) and pose your questions in a non-judgmental manner and avoid making assumptions about sexual orientation and gender identity.
- Ask for preferred pronouns and use those pronouns and support that patient’s current gender identity.
- Use ubiquity statements to normalize the topics you are discussing. These statements help patients understand that sexual concerns are common.

Female Patient Case: Ashley

Clinical History

- 33 years old
- African American
- Stage II breast cancer patient
- Recently had breast-conserving surgery
- Being treated with radiation

Social History

- Single
- Lesbian
- Lives alone
- Concerns about impact of lack of sexual desire and finding a partner

BLISSS

- **B**ring up the topic of sexuality
- **L**isten to **I**ndividual's experience and knowledge
- **S**upport the patient and partner
- **S**timulate and encourage patient-partner communication
- **S**upply individualized information, suggestions and resources; refer as appropriate

BLISSS: **B**ring up the topic of sexuality

BLISSS

Bring up the topic of sexuality

Listen to **I**ndividual's experience and knowledge

Support the patient and partner

Stimulate and encourage patient-partner communication

Supply individualized information, suggestions and resources; refer as appropriate

BLISSS: Listen to Individual's experience and knowledge

BLI**S**SS

Bring up the topic of sexuality

Listen to **I**ndividual's experience and knowledge

✓ **S**upport the patient and partner

Stimulate and encourage patient-partner communication

Supply individualized information, suggestions and resources; refer as appropriate

BLISSS: Support the patient and partner

BLISSS

Bring up the topic of sexuality

Listen to **I**ndividual's experience and knowledge

Support the patient and partner

✓ **S**timulate and encourage patient-partner communication

Supply individualized information, suggestions and resources; refer as appropriate

BLISSS: Stimulate and encourage patient-partner communication

BLISS**S**

Bring up the topic of sexuality

Listen to **I**ndividual's experience and knowledge

Support the patient and partner

Stimulate and encourage patient-partner communication

✓ **S**upply individualized information, suggestions and resources; refer as appropriate

BLISSS: **S**upply individualized information, suggestions and resources; refer as appropriate

Summary

- Bringing up issues of sex and sexuality are key to normalizing conversation and experiences.
- Patients may not bring up these topics on their own or may seem reticent to talk.
- Neither heteronormative or gender binary assumptions can be made. Be sure to ask as open-ended questions from the start!
- The more comfortable and open we are, the more willing our patients will be to talk to us and the more help they receive.
- Conversations should be ongoing and extend into survivorship.

Discussion

- How is the BLISS Model similar to or different than your current approach to discussing sexual health with your patients?
- Is there anything that you would add to the model?
- How can a model like BLISS inform your approach to addressing sexual health with your patients?