An Awkward Silence
Sexual Health and Cancer

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World Health Organization

Sexual Health

- State of physical, emotional, mental, and social well-being in relation to sexuality
- Sexual Health is more than penetrative intercourse or orgasm.
- Profound sexual dysfunction -> significant negative impact on quality of life.

Huffman LB, Hartenbach EM, Carter J, Rash JK, Kushner DM. Maintaining sexual health throughout gynecologic cancer survivorship: A comprehensive review and clinical guide. *Gynecol Oncol*. 2016;140(2):359-368.

An Awkward Silence

Sexual Health and Cancer

- Sexual quality of life (QoL) is crucial to the comprehensive care of patients.
- 2024 → estimated 19M gyn cancer survivors
- The prevalence of sexual dysfunction:
  - Approx 40% general U. S. population
  - Approx 90% in gyn oncology patients

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TREATMENT RELATED ADVERSE EFFECTS

- Sexual dysfunction is one of the most common and distressing consequences of cancer treatment (surgery, radiation, and chemotherapy)
- Approximately 50% women treated for cancer report cancer-related sexual concerns
- Sexual problems are not limited to women with breast or gynecologic cancers→ don't forget patients with other cancers (e.g., colorectal, bone marrow transplant, head and neck).
- Treatment-related sexual adverse effects can be short-term or long-term
- Long-term effects include treatment-induced menopause, altered gonadal function, and significant surgical disfigurement.
- Profound sexual dysfunction=a significant negative effect on quality of life.

TREATMENT RELATED ADVERSE EFFECTS

- **physical** (e.g., vaginal dryness, discomfort/pain during intercourse)
- **psychological/emotional** (e.g., decreased sexual interest, body image distress, low self-esteem/confidence, loss of femininity/masculinity)
- **interpersonal in nature** (e.g., changes in sexual scripts, loss of sex and intimacy)

Maree J, Fitch MI. Holding conversations with cancer patients about sexuality: Perspectives from canadian and african healthcare professionals. *Can Oncol Nurs J*. 2019;29(1):64-69

SEXUAL DYSFUNCTION

Disorders of sexual response

- arousal,
- erectile dysfunction,
- ejaculatory dysfunction
- reduced lubrication in females
- chronic dyspareunia
- orgasmic dysfunction

Disorders of sexual desire and motivation

- hypoactive sexual desire,
- reduced sexual motivation
- body image disturbances
- loss of sexual self-esteem

Zhou ES, Nekhlyudov L, Bober SL. The primary health care physician and the cancer patient: Tips and strategies for managing sexual health. *Transl Androl Urol*. 2015;4(2):218-231

Stabile C, Goldfarb S, Baser RE, et al. Sexual health needs and educational intervention preferences for women with cancer. *Breast Cancer Res Treat*. 2017;165(1):77-84.

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SEXUAL DYSFUNCTION

Although these problems have been well documented and there are a range of intervention strategies that can help patients cope with treatment-related sexual problems, many survivors do not feel prepared for potential sexual changes and often do not receive adequate support to manage sexual dysfunction.

Why the “silence” ???

An Awkward Silence

Sexual Health and Cancer

Misconceptions

- Cancer patients and survivors, don't have sex…
- Cancer patients and survivors aren't interested in sex and intimacy…
- Cancer patients and survivors should not be thinking about sex…

Conspiracy of Silence

The Stalemate

Patients may feel that if sexual health was important, their provider would mention the topic during the visit.

At the same time, providers feel that if it was important to the patient, the patient would bring it up.

Stalemate results as each side waits for the other….ultimately nobody brings it up…. resulting in ***"a conspiracy of silence".***

Sexual health and Cancer Survivorship, Kelly Johnson, Cure today 2016

Conspiracy of Silence
The Stalemate

- Numerous barriers contribute to this underprovided aspect of survivorship care
  - Lack of provider training and access to readily available resources.
  - Psychological, relational, and cultural factors significantly influence sexuality but are often not taken into consideration in research and clinical practice.
  - Sexual dysfunction and accompanying distress can be significantly alleviated with an integrative approach → provide survivors with appropriate screening, information, and support

Barriers : Providers Perspective

Why health care providers find it difficult to talk about sexual concerns ?

- time
- patient load
- clinic flow
- priority efforts are on disease care
- personal comfort
- lack of training and experience
- privacy in the clinic
- perceived role
- incentive

Dizon DS, Suzin D, McIlvenna S. Sexual health as a survivorship issue for female cancer survivors. *Oncologist*. 2014;19(2):202-210.

Barriers: Patient Perspective

Why patients find it difficult to talk about sexual concerns ?

- age
- culture
- private/personal topic
- embarrassment
- gender
- language
- being overwhelmed from the cancer
- trust and rapport with the professional
- time
- sexual orientation
- relationship between partners
- perceived role of professional

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Why is Sexual Health Important ?

The power of sexual intimacy is existential and should not be dismissed or underestimated by providers, patients, and their partners.

- May lead to lower grades of chronic disease and decrease chronic illness.
- Can influence hormones, improve emotional closeness, and boost immunity.
- Lower the risk of cardiovascular disease
- Decrease rates of both prostate and breast cancer.

1. Hall SA, Shackelton R, Rosen RC, Araujo AB. Sexual activity, erectile dysfunction, and incident cardiovascular events. *Am J Cardiol*. 2010;105(2):192-197.
2. Ho CH, Wu CC, Chen KC, Jaw FS, Yu HJ, Liu SP. Erectile dysfunction, loss of libido and low sexual frequency increase the risk of cardiovascular disease in men with low testosterone. *Aging Male*. 2016;19(2):96-101.
3. Brecher J. Sex, stress, and health. *Int J Health Serv*. 1977;7(1):89-101.

Why is Sexual Health Important ?

1

Unlike other post-treatment health issues (ie. pain), without intervention sexual problems tend to persist in cancer pts.→ which then can lead to long-term sexual distress → potential negative consequences for a patient's individual and relationship well-being.

2

Unaddressed treatment-related sexual dysfunction – as well as concern about potential sexual problems – can undermine care and directly compromises patient health-related outcomes in patients who undergo cancer-related treatment.→ treatment delay and/ non-compliance

3

Concerns about sexual side effects are a main reason for either delaying or ignoring recommendations for risk-reducing surgeries by women who carry a hereditary cancer mutation gene conferring high risk for breast and ovarian cancer.

4

ie, side effects of long-term cancer treatments, including difficulties with sexual arousal and desire, have been reported as key causes of early discontinuation or non-compliance to estrogen-reducing treatments or ovarian suppression for women with breast cancer.

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Breaking the Silence

- The American Society of Clinical Oncology (ASCO) guideline for sexual problems recommends that oncology providers initiate a dialogue about sexual health and dysfunction with all cancer patients at the time of diagnosis and throughout their care. Partners may be included in the discussion, if the patient agress.

- The National Comprehensive Cancer Network (NCCN) also recommends that sexual function screening be conducted at regular intervals.

- Screening tools for men and women that oncology providers can use during visits
  - Female Sexual Functioning Index (FSFI)
  - Hamilton Depression Inventory (HDI),
  - Body Image Survey (BIS),
  - Marital Satisfaction Inventory-Revised (MSI-R)

Denlinger CS, Sanft T, Baker KS, et al. Survivorship, Version I.2018. NCCN Clinical Practice Guidelines in Oncology. July 30, 2018.https://www.cancertherapyadvisor.com/home/tools/fact-sheets/sexual-health-and-cancer-treatment/2/

Talking to Patients About Sex and Intimacy

Validate and normalize the experience of sexual problems

- "Most survivors who have been through this kind of treatment find themselves facing changes in sexual function."
- "Can you tell me about the impact that cancer has had on sexuality or intimacy for you?"
- "Sometimes talking can help. Is there anything else about your sexual health that has been bothering you?"

--Adapted from Resources-for-Oncology-Nurses. Bober & Vareia. J Clin Onc 2012;30:3712--9

Basson
Non-linear Model of Sexual Response

The traditional model Sexual response = straight line from desire to arousal to plateau to orgasm

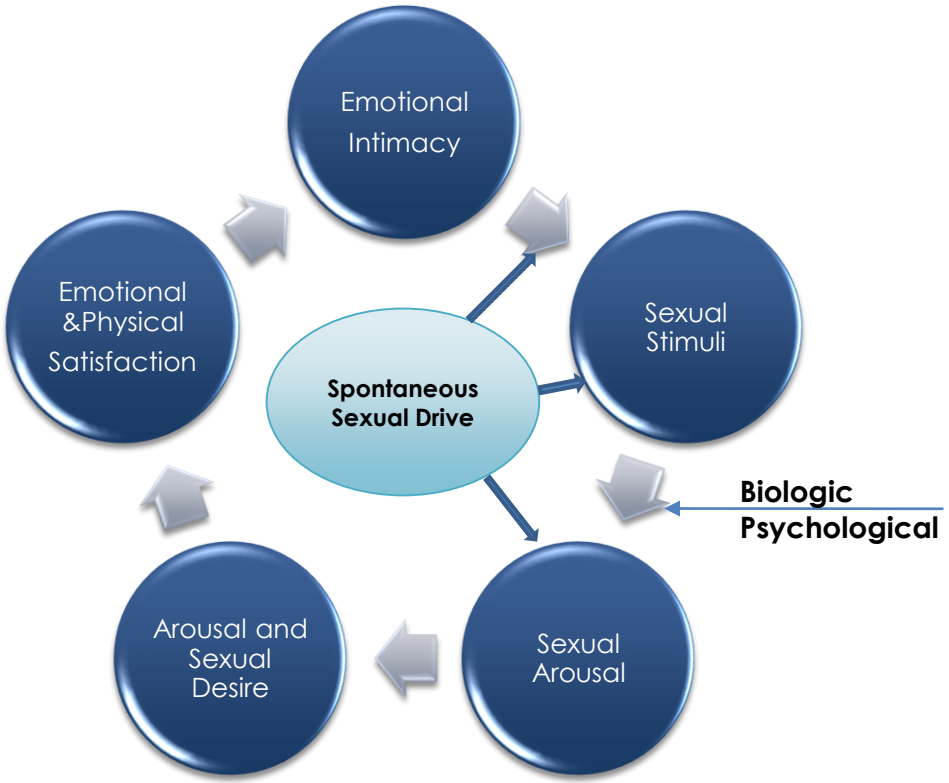
Basson Model→ sexual experience is a cycle of overlapping phases influenced by mental and physical factors.

Women may not often feel spontaneous desire→ wish for intimacy or express love → arousal→ sexual contact→ desire

"Initial desire is desirable, if you like, but not mandatory",

https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(07)60176-7/fulltext

Basson
Non-linear Model of Sexual Response

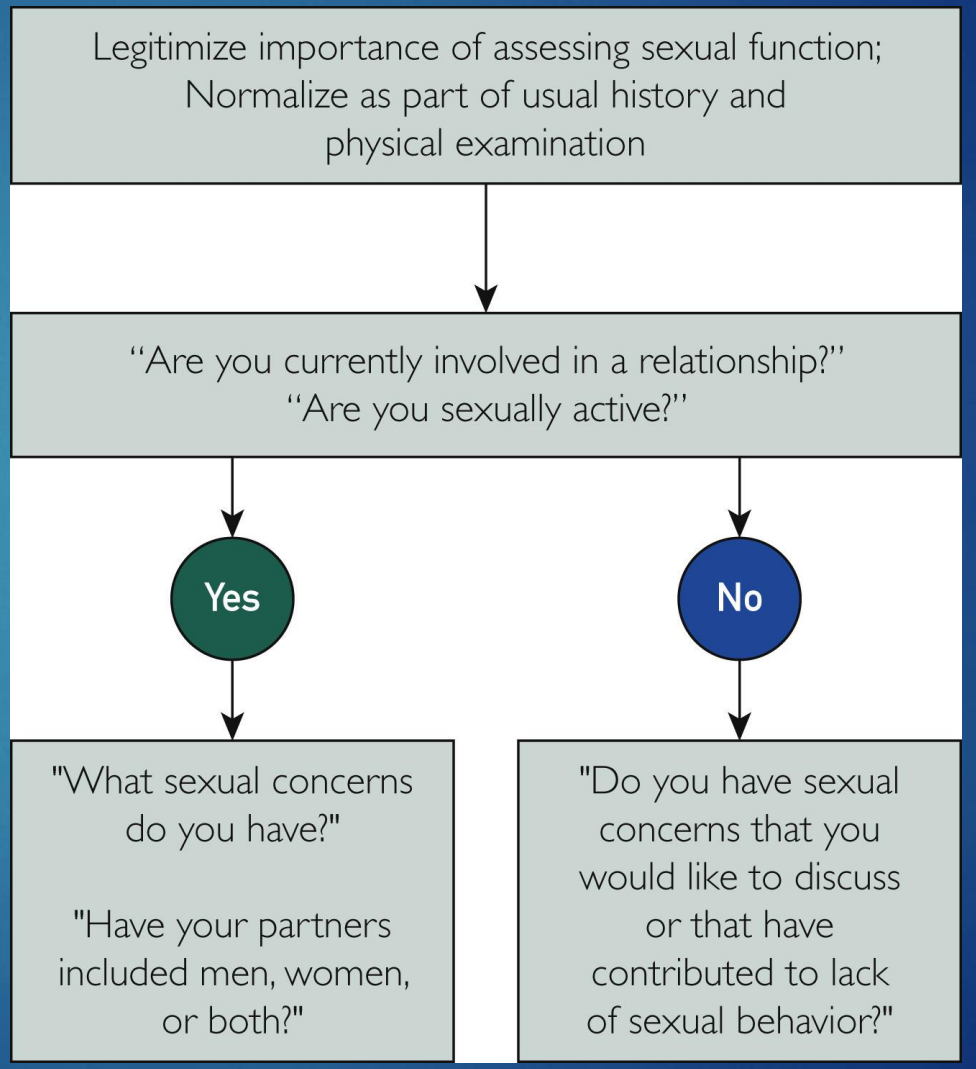


KISS = Keep It Short & Simple

- Encourage all practitioners to address sexual function in their patients
- Basic assessment of sexual functioning can be useful and limited to a small number of specific questions with minimal time involvement.
- It is essential to inquire about the gender of partners.
- Do not make assumptions about sexual orientation and behavior→ not all patients identify as heterosexual or engage exclusively in heterosexual sexual behavior

Mayo Clinic Proceedings 2019 94, 842-856DOI: (10.1016/j.mayocp.2019.01.009)

Basic screening algorithm for sexual function



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Brief Sexual Symptom Checklist For Women.

Please answer the following questions about your overall sexual function:

1. Are you satisfied with your sexual function? ❑ Yes ❑ No

If no, please continue.

2. How long have you been dissatisfied with your sexual function? _____

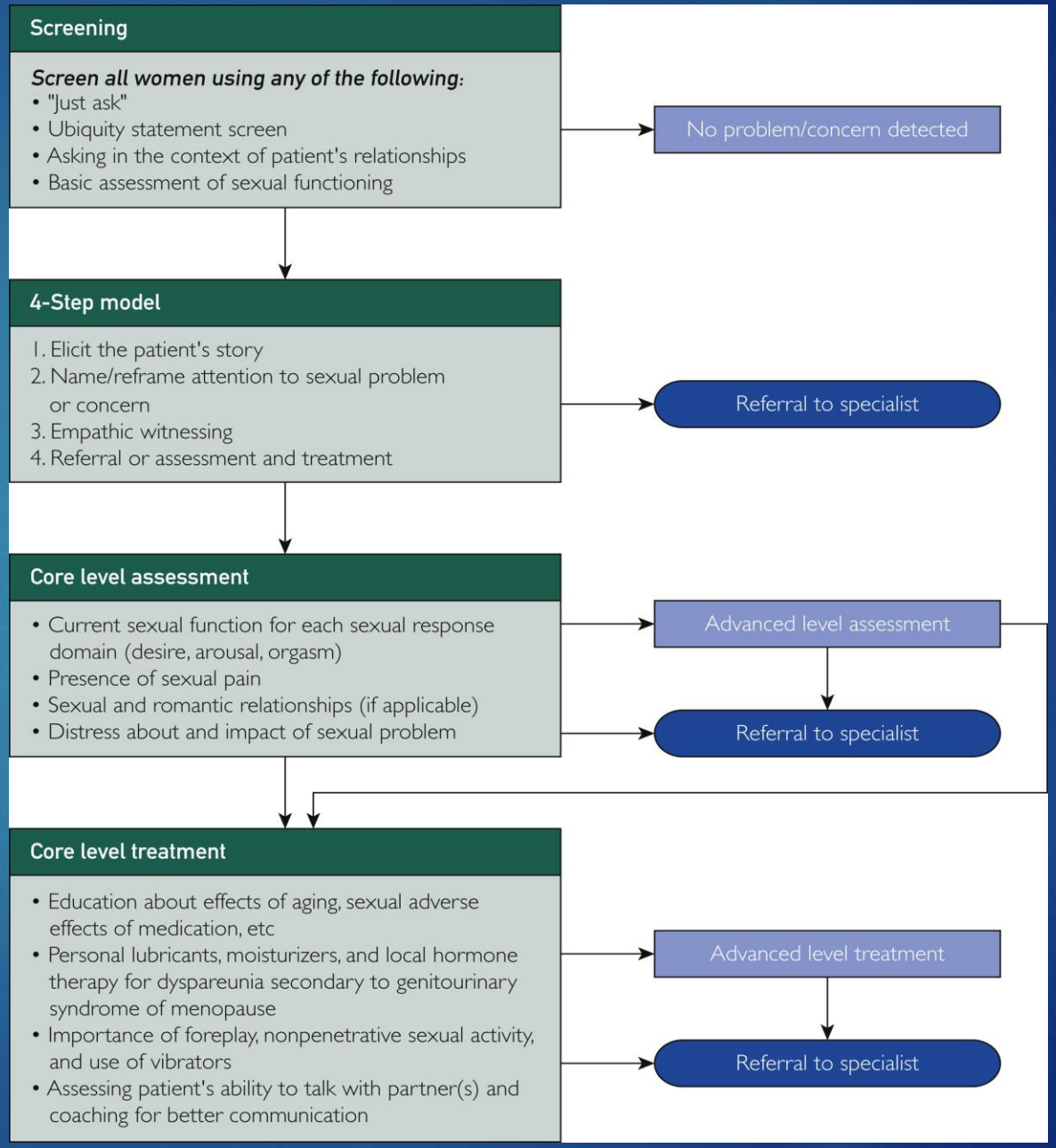
3. Mark which of the following problems you are having, and circle the one that is most bothersome:
   - ❑ Little or no interest in sex
   - ❑ Decreased genital sensation (feeling)
   - ❑ Decreased vaginal lubrication (dryness)
   - ❑ Problem reaching orgasm
   - ❑ Pain during sex
   - ❑ Other: _____

4. Would you like to talk about it with your doctor? ❑ Yes ❑ No

1.
Adapted with permission from Hatzichristou D, Rosen RC, Derogatis LR, et al. Recommendations for the clinical evaluation of men and women with sexual dysfunction. J Sex Med. *2010;7(1 pt 2):346*.
https://www.aafp.org/afp/2011/0915/p705.html

International Society for the Study of Women's Sexual Health

Process Of Care for the Identification of Sexual Concerns and Problems in Women.



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Break the Silence

EX-PLISSIT Model

- Permission
- Limited information
- Specific suggestions
- Intensive therapy

5As Model

- Ask
- Advise
- Assess
- Assist
- Arrange

EX-PLISSIT MODEL

- **EX** → ask permission at each stage allowing the patient to be curious and ask questions. It is essential for the patient to feel comfortable offering sexual health information
- **P**ERMISSION: obtain patient's permission to open a dialogue about sexual issues. Remain open, nonjudgmental, and receptive
- **LI**MITED **I**NFORMATION: obtain limited information from patients about specific/targeted sexual effects of treatments
- **S**PECIFIC **S**UGGESTIONS: based on full evaluation
- **I**NTENSIVE **T**HERAPY: referrals to include psychological counseling, sex therapy, physical therapy

Almeida NG, Britto DF, Figueiredo JV, Moreira TMM, Carvalho, R E F L, Fialho AVM. PLISSIT model: Sexual counseling for breast cancer survivors. *Rev Bras Enferm*. 2019;72(4):1109-1113.

5 A's MODEL

ASK—'asking' signals validation. Start with a simply statement such as " Many women who have gone through similar cancer treatment notice changes in sexual function or vaginal health ."

ADVISE—A brief but important opportunity to *advise* patients that problems can be addressed. ie " Fortunately there are lots of resources for women with your concerns ."

ASSESS—Using a checklist/ validated questionnaire, providers can evaluate current concerns

ASSIST—*Empower* patients by providing education, information and resources (referrals for counseling, pelvic physical therapy, urogynecology consult, etc

ARRANGE Follow-up—final step serves as a reminder to providers/staff to organize *follow-up* for identified problems and to follow up by "initiating inquiry" at the next visit.

Bober SL, Reese JB, Barbera L, et al. How to ask and what to do: A guide for clinical inquiry and intervention regarding female sexual health after cancer. *Curr Opin Support Palliat Care*. 2016;10(1):44-54.

Managing Conversations About Sexual Health

Set a standard of care to inform all patients about the impact of cancer treatment on sexuality.

Inform patients about side effects and the impact on sexuality.

Basic assessment to include questions about sexual concerns and whether the patient wants help.

Develop a list of referral resources

Hold staff accountable for including sexuality as a routine/standard part of their practice.

Urge staff to regularly check with patients about sexual concerns

staff training programs on sexuality assessment and interventions

Have educational resources about sexuality available

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Provider and Staff Education

- Early sexual health training of medical and mental health professionals
- Training for medical/APP/nursing students to include conducting a sexual history.
- Education about how sexuality is experienced for individuals at various stages of development and across different cultures and sexual minorities
- At a minimum, education for oncology providers should include :
  - A background in sexual health and function,
  - Etiology of sexual health changes due to cancer treatments,
  - Current research supporting treatments for these issues.
  - CME training / Workshops to help clinicians currently in practice in improving their skills.

KEY POINTS TO ENSURING A PRODUCTIVE SEXUAL HEALTH 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 ("partner") and pose your questions in a non-judgmental manner.

- Avoid making assumptions about your patient based on age, appearance, marital status, or any other factor. Unless you ask, you can't know a pt's sexual orientation, behaviors, or gender identity.

- Try not to react overtly, even if you feel uncomfortable or embarrassed. Pay attention to your body language and posture.

https://nationalcoalitionforsexualhealth.org/tools/for-healthcare-providers/document/ProviderGuide.pdf

KEY POINTS TO ENSURING A PRODUCTIVE SEXUAL HEALTH CONVERSATION

- Ask for preferred pronouns or terminology when talking to a transgender patient. Use those pronouns and support that patient's current gender identity, even if their anatomy does not match that identity.

- Rephrase your question or briefly explain why you are asking a question if a patient seems offended or reluctant to answer.

- Use ubiquity statements to normalize the topics you are discussing. Help patients understand that sexual concerns are common.

- Ensure that you and your patient share an understanding of the terms being used to avoid confusion. If you are not familiar with a term your patient used, ask for an explanation.

https://nationalcoalitionforsexualhealth.org/tools/for-healthcare-providers/document/ProviderGuide.pdf

TAKE HOME POINTS

- Providers need to initiate the conversation of sexual concerns.
- 5A's and EX-PLISSIT are simple effective tools to facilitate an on-going dialogue
- Simple strategies can be implemented into clinical practice to discuss and treat many sexual issues.
- Referral to specialized sexual health providers may be needed to address more complex problems.
- Cancer related changes in sexual interest, activity and satisfaction are considered "normal "

TAKE HOME POINTS

Providers can make a significant impact on the QoL of cancer patients and survivors by addressing sexual health concerns.

- Tailor the approach
  - culture
  - local sensitivities,
  - gender
  - age
  - language.
- Set clear expectations for the practice
  - Staff members need to be clear about their roles and what is expected of them regarding holding conversations about sexuality.

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Thank you for your time and attention.

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