



Shari Goldfarb, MD
Breast Medicine Service
Health Outcomes Research Group
Memorial Sloan Kettering Cancer Center
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Overcoming Barriers

MASCC/ISOO

Annual Meeting on Supportive Care in Cancer

www.mascc.org/meeting

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MASCC
Multinational Association
of Supportive Care in Cancer

ISOO
International Society
on Oncology Supportive Care



#MASCC19

Disclosures

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Cancer Consequences that Affect Sexuality

- Ongoing fatigue
- Body image concerns
 - Alopecia
 - Weight changes
 - Surgical scars
- Impaired immune response
- Hormonal changes (transient or permanent amenorrhea)
- Infertility
- Depression
- Anxiety
- Family distress
- Increased risk of osteoporosis (fear of fractures)



Premature Menopause

- Menopause in the cancer patient is different
 - Abrupt or premature hormonal deprivation
 - Greater intensity and duration of symptoms
 - Negatively impacts QoL
- Special patients to consider
 - Breast cancer patients on endocrine therapy
 - Bone marrow transplant patients
 - Older women on HRT
 - Patients treated with intravaginal radiation
 - Woman with breast reconstruction and loss of sensation in their nipples



Common Sexual Problems After Breast Cancer Treatment: Prevalence Table

| Most Common Sexual Problems | Prevalence | References |
|-----------------------------|------------|--|
| Overall | 30%–100% | Sadovsky et al. |
| Overall | 76% | Goldfarb et al. |
| Desire | 23%–64% | Bloom et al., Arora et al., Fobair and Spiegel, Barni and Mondin, Burwell et al. |
| Arousal or lubrication | 20%–48% | |
| Orgasm | 16%–36% | |
| Pain/dyspareunia | 35%–38% | |
| Body image concerns | 30%–67% | Fobair et al., Figueiredo et al. |
| Poor nipple sensation | > 90% | Djohan et al. |



2019

21-23 JUNE

SAN FRANCISCO

SUPPORTIVE CARE
MAKES EXCELLENT
CANCER CARE POSSIBLE



Clinicians Don't Always Discuss Sexual Health with their Cancer Patients

Most Common Barriers

- Lack of time
- Lack of resources
- Unaware how to discuss the problem and where to refer patients
- No training on how to treat sexual dysfunction
- Attitudes and emotional state of patient

Patient Factors

- More likely to discuss if recently engaged or married
- Less likely if older
- Less likely if already have aggressive disease, poor prognosis, gay, HIV-positive

Most often discussed if patient brings it up



Cancer and Sexuality Discussions

- Changes in sexual health often cause distress
- When distress is high, sexual desire is low
- A decreased libido may cause confusion and embarrassment
- Many patients are not cognizant that their sexual problems are related to their treatment (**normalize**)
- Patients don't initiate discussions with their physicians, but often want to talk about their issues
- **Healthcare providers should initiate discussions**





How can we help our patients?



Overcoming Barriers

- **Communication**
- Develop patient and clinician resources
- Perform RCT to develop evidence based recommendations
- Learn local resources
- Most difficult barrier to overcome is time



PLISSIT

- Permission
- Limited Information
- Specific Suggestions
- Intensive Therapy



PLISSIT

Permission:

- Clinicians should initiate a discussion about intimacy, sex and sexuality
- Never make assumptions about sexual orientation or history (use neutral language)
- Offer patients permission for sexual difficulties to exist (sequelae of disease and treatment)
- Legitimize sexual concerns



PLISSIT

Permission:

- Explain how treatment may impact a patient's thoughts, relationships, and sexual health (normalize)
- Address building and maintaining friendships and intimate relationships
- Discuss safe sex techniques
 - Have pre- and post treatment discussions
 - Patients may believe they are infertile and therefore excused from practicing safe sex
 - Recommend barrier contraception during treatment



PLISSIT

Specific Suggestions:

- Understand how intimacy, sexuality and pleasure were achieved before cancer
- Redefine the “new” normal
- Help patients practice disclosing their survivorship
- Offer suggestions to address problems:
 - Take pain meds 30 mins before intimacy
 - Place pillow under joints to improve comfort
 - Vaginal dilators, lubricants, moisturizers, intravaginal estrogen or DHEA
 - Flibanserin for decreased libido



PLISSIT

Limited Information:

- Address myths
 - Assure pts its ok to have intercourse during treatment
- Discuss how cancer and treatment affect intimacy and sexual relations
- Address the impact of fatigue and anxiety
- Connect patients with peer support groups, websites, retreat programs and sexual health clinics
 - Help decrease feelings of isolation and helplessness



PLISSIT

Intensive Therapy:

- Offer patients a safe place to express feelings
- Help explore issues with patients and partners
- Refer to a multidisciplinary team
 - Physical therapist-pelvic floor therapy
 - Oncology social worker
 - Psychiatrist/psychologist
 - Urologist
 - Gynecologist
 - Sex therapist



Barriers to Effective Communication

- Giving pathophysiology lectures
- Ignoring the context of the communication encounter
- Not finding out the patient's information need
- Launching into your agenda first without negotiating the focus of the interview
- Offering reassurance prematurely



Tips for Effective Communication

- **Three Core Communication Skills**
 - Asking open ended questions
 - Listening and allowing for silence, reflection, summarizing
 - Informing
- **Ask Tell Ask**
 - **Ask an open-ended question** – “Tell me what you know about...”
 - Learn what the patient thinks that is correct and mistaken
- **Assess resistance to change and what patients need from you**



Shared Decision Making

- All parties are experts in their own right
 - Healthcare team in medical knowledge including prognosis and safety of particular treatments
 - Patient expertise in experience of illness, treatment, values and importance of sexual dysfunction in their life
- Decision is made with all parties sharing all the information relevant to decision
 - Patients need to be empowered to present their concerns, values and beliefs and make appropriate treatment decisions for themselves regarding their sexual function
 - Healthcare provider needs to be able to educate about disease and prognosis effectively and risks, benefits and side effects of all types of treatment



Decision for Treatment is a Balance Between Perceived Need & Concerns

**Perceived need
for treatment**

**Concerns about
treatment**



Resources

- Know where to refer patients
 - ISSWSH and NAMS websites to find a provider
- Scientific Network on Female Sexual Health and Cancer
 - Interdisciplinary network of clinicians, researchers and healthcare professionals with a goal to promote sexual well being in all women and girls affect by cancer
 - Courses on how to start sexual health clinics



How Do Patients Want to Receive Sexual Health Information?

- Patients prefer to review and discuss written information with their medical team (age <50 years: 74%, n=83; age ≥50 years: 58%, n=61).
- Older women preferred to read material on their own (52%, n=55, p=0.012)
- Younger women wanted to discuss them with the medical team directly (74%, n=83, p<0.017)
- Younger women reported more interest in the online intervention modality (58%, n=65, p<0.001).
- Older women were not as interested in participating in the online sexual health interventions despite having computer access.



Thank you

