Identifying, Assessing, and Treating Cancer-Related Sexual Dysfunction

Leslie R. Schover, PhD
CEO, Will2Love.com
Learning Objectives

After attending this presentation, you should be able to:

1. Describe 5 psychosocial or medical risk factors for sexual dysfunction in men or women with cancer

2. Apply 2 alternate strategies for identifying patients who have sexual concerns

3. Use 3 techniques to discuss sexual issues with patients

4. Describe the rationale for multidisciplinary treatment of cancer-related sexual dysfunction
DISCLOSURE

Relevant Financial Relationship(s)
CEO and owner of Will2Love, LLC, a digital health company focusing on cancer and reproductive health

Off Label Usage
None
60% of cancer survivors end up with long-term sexual dysfunction
Fewer than 25% of this group gets professional help
2017 ASCO and NCCN practice guidelines for cancer-related sexual problems agree:

The oncology team should initiate a discussion of sexuality and cancer during treatment planning and periodically at follow-up visits.

Further psychosocial and medical assessment should take place when a concern or problem is identified.

Referrals should be offered for multidisciplinary treatment, since sexual problems frequently have both psychosocial and physiological causes.


NCCN Updated guideline: [Journal of the National Comprehensive Cancer Network](http://www.jnccn.org) 2017 Sep;15(9):1140-1163
Fulfill new Commission on Cancer 2020 Survivorship Program Standard

Instead of focus on survivorship care plans, a cancer center chooses at least 3 areas of survivorship care to enhance and document.

One highlighted service to include is formalized referrals to experts in sexual dysfunction, fertility counseling.

Will2Love can provide online interventions; document uptake, patients served, and outcomes; and train staff to do billable assessments that create referrals for patients.

NCCN Updated guideline: Journal of the National Comprehensive Cancer Network 2017 Sep;15(9):1140-1163
Barriers to optimal reproductive health care

Lack of professional training: Clinicians have limited time and skills to manage reproductive issues; Not aware that sexual function ranks in top 5 unmet needs of cancer survivors

Concern that care for reproductive health will not be reimbursed: To maximize revenues, hospitals need optimal workflows and CPT codes

Anxiety: Patients reluctant to bring up topics of sex and fertility
Need for Flexible Timing of Dialogue

- Concern about sex may affect cancer treatment choices
- Some physical damage may be prevented by penile or vaginal “rehab” starting during or just after cancer treatment
- Since patients often live far away, may need to provide major info in one session and provide telehealth follow-ups
- Many patients seek help years later or not at all and could have been spared much suffering
Need for Multidisciplinary Care

- Damage is physiological, but ability to cope and maintain an active sex life depends on individual coping skills and quality of relationship
- Goals of brief counseling:
  ✓ Integrate medical interventions into sexual routine
  ✓ Improve sexual communication
  ✓ Improve pleasure for both partners,
  ✓ Encourage wider concept of “normal” sex
- Coordinate with medical specialists
What Do Surveys of Oncology Professionals Tell Us?

• They agree that sexuality is important to discuss.
• They rarely bring it up unless the patient does.
• They think it is someone else’s job:
  • “The ________ should be talking about that.” [insert another professional group]
Sex: The Hot Potato of Patient – Healthcare Professional Communication
What Is Sexuality?

Health Care Professionals vs. Patients

• Health care professionals view sexual problems in narrow, medical terms
• Focus on problems that interfere with heterosexual intercourse
• Patients want help with wide array of sexual issues: Impact on relationship, body image, self-concept
• Key issue is acceptance of noncoital sex as normal and pleasurable
Common Sexual Problems and Risk Factors for Them
Common Sexual Problems Related to Cancer Treatment

Pervasive, severe and persistent

- Loss of desire and pleasure
- Male erectile dysfunction
- Female genital dryness and pain
- Difficulty and changes in orgasm
- Urinary and bowel incontinence
- Rarely go away without treatment
## Women at High Risk for Sexual Dysfunction

<table>
<thead>
<tr>
<th>Sexual Problem</th>
<th>Cancer Treatments that Increase Risk</th>
<th>Mechanism</th>
</tr>
</thead>
</table>
| Loss of desire for sex and trouble feeling aroused | • High-dose chemotherapy  
• Aromatase inhibitors  
• Immunotherapy | • Damage to brain centers  
• Loss of estrogen in brain  
• Secondary endocrine changes  
• Chronic fatigue, pain, nausea, distress, damaged body image  
• Psychotropic or pain medication |
| Genitourinary atrophy, dryness, and pain | • Abrupt, premature ovarian failure (chemotherapy, pelvic XRT, GnRH agonist or antagonist, bilateral oophorectomy)  
• Exacerbation of normal menopause (aromatase inhibitors)  
• Pelvic radiation therapy  
• Genital graft vs. host syndrome | • Severe estrogen deprivation and genitourinary atrophy  
• Loss of elasticity, lubrication with loss of blood supply to genitals  
• Scar tissue from pelvic surgery or radiotherapy  
• Inflammation and adhesions from graft vs. host syndrome |
# Women at High Risk for Sexual Dysfunction

<table>
<thead>
<tr>
<th>Sexual Problem</th>
<th>Cancer Treatments that Increase Risk</th>
<th>Mechanism</th>
</tr>
</thead>
</table>
| Difficulty experiencing pleasure and reaching orgasm | • Damage to spinal cord from tumor, surgery or radiation  
• Loss of erotic breast sensation | • Loss of physiologic sensation  
• Secondary effects of low desire/arousal and pain |
| Urinary or bowel incontinence | • Creation of ostomy  
• Pelvic radiation therapy  
• Surgery for pelvic cancer | • Trouble managing ostomy during sex  
• Scarring and contraction of organs  
• Changed anatomy |
<table>
<thead>
<tr>
<th>Sexual Problem</th>
<th>Cancer Treatments that Increase Risk</th>
<th>Mechanism</th>
</tr>
</thead>
</table>
| Loss of desire for sex and trouble feeling aroused | • High-dose chemotherapy  
• Cranial irradiation  
• Immunotherapy                                                                                     | • Possible damage to brain centers                                                                 |
|                                                    |                                                                                                     | • Possible hypogonadism                                                                            |
|                                                    |                                                                                                     | • Stigma of erectile dysfunction                                                                   |
|                                                    |                                                                                                     | • Chronic fatigue, chronic pain syndromes, nausea, distress, damaged body image                    |
| Erectile dysfunction                               | • Damage to pelvic autonomic nerve bundles (neurotoxic chemotherapy, pelvic surgery)  
• Pelvic radiation therapy or total body irradiation                                               | • Nerve damage limits blood flow during erections                                                  |
|                                                    |                                                                                                     | • Venous leakage during erection                                                                   |
|                                                    |                                                                                                     | • Direct loss of blood supply to penis                                                              |
|                                                    |                                                                                                     | • Penile curvature and scarring                                                                     |
## Men at High Risk for Sexual Dysfunction

<table>
<thead>
<tr>
<th>Sexual Problem</th>
<th>Cancer Treatments that Increase Risk</th>
<th>Mechanism</th>
</tr>
</thead>
</table>
| Difficulty experiencing pleasure and reaching orgasm | • Damage to spinal cord from tumor, surgery or radiation  
• Genital graft vs. host syndrome | • Loss of physiologic sensation  
• Secondary effects of low desire/arousal and pain  
• Ejaculatory changes: dry orgasm, pain, climacturia |
| Urinary or bowel incontinence | • Creation of ostomy  
• Pelvic radiation therapy  
• Surgery for pelvic cancer | • Trouble managing ostomy during sex  
• Scarring and contraction of organs  
• Changed anatomy |
Sexual Function and Quality of Life

• Cancer-related sexual problems are associated with poor quality of life and depressed mood in repeated studies

• Sexuality is important and valued for most patients/partners

• Treating sexual problems often reduces general distress levels
Concerns about Safety of Sexual Activity

• Great majority of cancer patients and survivors can be sexually active
• Sex not safe during brief periods after pelvic radioactive seed implants, during surgical recovery, during severe immunosuppression, or if bleeding from genital tumor
• Cancer cannot be sexually transmitted; HPV, HIV and cancer risk; vaccine important
• Important to have safer sex to prevent sexually transmitted infections during times of immunosuppression
• No clear evidence that chemotherapy in semen or vaginal fluids can harm partner, but may wish to use barrier contraception during half-life of drugs, especially if female partner could become pregnant or is pregnant
Are Screening Questionnaires Helpful?

• PROMIS Brief Sexual Profiles for Men and Women

• Female Sexual Function Index (FSFI) 19-items but may be biased for women who are not sexually active

• International Index of Erectile Function (IIEF) 15 items measuring most aspects of sexual function; urologists often just use the erection items
Limitations of Questionnaires

• Patients often skip items out of embarrassment or poor comprehension

• Staff often fail to review or discuss patient’s questionnaire

• Result: Added patient frustration
A Reproductive Clinic System

Ask one question to identify a concern about sexual health or fertility

Prescribe online self-help program for men or women

Schedule billable assessment session with APN/PA trained with Pro Portal

Refer as needed for counseling (in-person or telehealth)

Refer as needed for medical specialty care (GYN, urology, infertility)
Clinician 4-Step Action Plan
Step 1: Routinely identify problems and concerns

Ask one question at each visit, prefaced by a normalizing statement: Many people worry that cancer treatment will damage their sex life or fertility. Do you have a question or concern?
Step 2: Provide online self-help and option of expert assessment

• Offer brochure with registration code to set up free 6-month subscription to Will2Love’s online self-help program for men or women
• Ask if patient would like an assessment visit with trained advanced practitioner
Step 3: Schedule assessment visit with clinic “sex expert”

- Trained to assess and manage cancer-related reproductive health problems
- Can “prescribe” online self-help programs (navigators help with lower literacy patients)
- Can conduct assessment visit (billable with E & M codes if advanced practitioner)
- Makes appropriate referrals for specialty care (yielding additional revenue for in-house services)
Online training and support for oncology professionals

- Skills to comfortably discuss sexual topics
- Clinician’s manual on how to use self-help programs with patients
- Assessment interview outlines
- Treatment algorithms for specific sexual problems combining resources from self-help programs with options for medical treatment
- 9 online webinars to supplement website, each with downloadable handout
- Useful to train clinic “sex expert” or to enhance knowledge of mental health professionals without sex therapy training
Step 4. Care provided by your network of specialty referrals

• Mental health professionals trained in both psycho-oncology and sex therapy

• Gynecologists trained to treat menopause symptoms and pelvic pain

• Urologists trained to treat male sexual problems

• Pelvic rehabilitation specialty physical therapists

• When specialty clinics are available within a large cancer center or affiliated health care system, revenue from increased referrals more than offsets cost of contract
Developing an Evidence-Based Online Self-Help Intervention: Stand Alone or Clinician-Guided
Personalized online self-help programs for all cancer types

• Use as stand-alone program or as adjunct to counseling
• Explain sexual side-effects of specific sites and treatments
• Present step-by-step self-help solutions to prevent or overcome sexual problems
• Help patients understand and choose medical treatment options
• Tested at MD Anderson with 3 successful, published efficacy trials
• Recent pragmatic trial in partnership with American Cancer Society
• Other online programs developed in Australia, Sweden, the Netherlands
Internet vs. face-to-face sex therapy randomized trial for prostate couples

- 124 couples, 3 months to 7 years post-treatment for localized prostate cancer
- Randomized: 1) 3-month waitlist control 2) 3 face-to-face sessions with handouts 3) online intervention, web site and email with counselor
- Intervention content same, plus relapse prevention, written and phone

Internet vs. face-to-face trial outcomes

- No improvement during waitlist control
- Intervention equally effective in both groups, significant improvement baseline to 12-mo FU for IIEF ($P<.001$) and dysfunctional women FSFI ($P=0.03$)
- IIEF scores improved more in men completing at least 75% of web intervention
- 34% dropout rate, no between-group difference
Randomized trial of female internet intervention: Design and demographics (N=58)

- 12-week treatment website only vs. website + 3 sessions
- Follow-up at 6 months post-treatment
- Questionnaires: Baseline, Post-TX, 3-months, 6-months
- Mean age 53 ± 9, 89% married
- 79% Anglo, 9% AA, 10% Hispanic, 2% other
- 12% < HS, 29% some college, 59% ≥ college
- 81% breast cancer, 19% GYN cancer
- 97% in menopause, 9% on estrogen, 4% testosterone

FSFI by Group and Time

![Graph showing FSFI by Group and Time](image)

- **Self-Help**
- **Counseled**

Baseline | Post-TX | 3-mo FU | 6-mo FU
--- | --- | --- | ---
10.0 | 20.0 | 15.0 | 12.0
Linear Mixed Models of Outcomes, Baseline to Post-Treatment, Combined Groups

<table>
<thead>
<tr>
<th>Outcome (Total Score)</th>
<th>Mean Difference</th>
<th>P-level</th>
</tr>
</thead>
<tbody>
<tr>
<td>FSFI</td>
<td>3.41</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>MSIQ</td>
<td>6.54</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>BSI-18</td>
<td>-2.96</td>
<td>0.001</td>
</tr>
<tr>
<td>QLACS</td>
<td>-13.73</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

- Counseled group improved significantly more than self-help group on FSFI (P= 0.024) and MSIQ (P=0.011)
- Gains remained significant from post-treatment to 6-month follow-up except for MSIQ in counseled group
TIME SPENT ON WEB SITE

• Time spent on web site (excluding completion of questionnaires) electronically recorded
• Average was about 2.5 hours, highly variable
• Total usage time related to change in MSIQ at 6 month FU (P=0.06)

<table>
<thead>
<tr>
<th>Group</th>
<th>Minutes during 12-week treatment</th>
<th>Minutes during 6-month FU*</th>
<th>Total minutes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-Help</td>
<td>108.6 ± 141.9</td>
<td>38.6 ± 60.9</td>
<td>147.2 ± 174.5</td>
</tr>
<tr>
<td>Counseled</td>
<td>143.4 ± 134.8</td>
<td>7.6 ± 17.7</td>
<td>151.1 ± 137.7</td>
</tr>
</tbody>
</table>

*P<.001 between groups during follow-up
Pragmatic Trial of Online Interventions in Sexuality and Cancer (with ACS Behavioral Research Center)

• 280 participants completed baseline: 76% female, mean age 54, 78% married, 74% with college degree or more, 90% Caucasian. Diagnoses included 53% breast, 12% gynecological, and 13% prostate.

• Attrition was high: 39% completed 3-month questionnaires.

• Due to power limitations, analyses only conducted for female patients.

• 197 completed baseline; 60 (30.4%) accessed website ≥ 1 time and completed 30-month questionnaires; Spent mean of 82.2 (116.0) minutes on the website during the 3 months of the study.

• Site users were more likely to be sexually active at follow-up (P<.001), used more sexual aids at follow-up (P=.01), reported improved sexual function/satisfaction (P<.001).

• Intention to treat analyses had same significance.

Journal of Sex & Marital Therapy, online May, 2020
Comments and results helped us design new onboarding to boost patient engagement

• Brief questionnaire personalizes home page content by gender, age, partner vs. patient, cancer site and treatment types, specific sexual problems, interest in parenthood, relationship enhancement, dating, parent of survivor

• New user gets “tour” of website features including personalized links, search features, bookmarking

• User is guided to set first 3 goals: knowledge, action, and relationship

• Email reminders to log into site, complete goals, etc.
Personalized Home Page

HIGH-PRIORITY LEARNING AND SELF-HELP

Basics
- What is Normal Sex for Women?
- Does Menopause Change Women’s Sex Lives?
- How Cancer Treatment Can Damage Sex Life
- When is it Safe to Have Sex?

Explore
- My Cancer Treatment
- My Relationships
- My Sexuality
- Fertility and Parenthood

VIEW AND SET YOUR GOALS
- How to set your goals
- Set your goals
- My goals and progress
- My Week 12 Plan
- Example of a Week 12 Plan

MY REMINDERS & BOOKMARKS

MY REMINDERS
There are currently no reminders.

MY BOOKMARKS
If you do not see the bookmarks you have previously saved in this section, click the button above.
- Getting Pregnant after Cancer
- Keep Your Sex Life Alive!
- Overcoming Vaginal Dryness and Pain
Conclusions

• Oncology practice settings have typically ignored sexual health

• Online interventions show promise as stand-alone programs to overcome barriers of inadequate staff time and training

• With the right training, tools, and workflow, a reproductive health program can improve patient quality of life and meet clinical practice guidelines