Sexual Life after Breast Cancer

Sharon Bober Ph.D
Director, Sexual Health Program
Dana-Farber Cancer Institute/ Harvard Medical School

October 9, 2018
Sexual Function: What Do We Know?

• 66% of young women remain sexually active through treatment

• Higher rates of sexual dysfunction compared to healthy controls

• 40-80% of younger survivors report distressing sexual side effects
  • 50% of young women report problems in two or more areas of function

• Majority of survivors report not receiving support for sexual problems in context of cancer care

How are Sexual Side Effects Different?

- Unlike other treatment-related side effects, sexual symptoms do not self-resolve.
- Untreated sexual dysfunction tends to worsen over time.
What Young Women Say...

“Of course I’m grateful to be alive, but sex is painful and it’s like all the sudden I feel like I am an old woman.”
- 42 yr old woman

“I just don’t feel much sensation - either upstairs or downstairs. So much of me is just gone. I try to avoid thinking about it because I don’t have much desire anymore.”
- 36 yr old woman

“My husband is a saint but I know this is affecting our relationship...it's hard to talk about it. I don’t feel like a whole person anymore.”
- 40 yr old woman
Categories of Sexual Dysfunction after BR Cancer

Body Image/ Sexual Self-Esteem / Identity

Relationship Intimacy/Partner Communication

Vaginal Health / Hypoestrogenism/ Menopause

Desire/ Arousal/ Sexual Satisfaction

Casey et al, World J Clin Oncol, 2014; Gilbert et al, Maturitas, 2010
Sexual Dysfunction and QOL

For young BR CA survivors, untreated sexual symptoms also associated with:

- Anxiety
- Depression
- Loss of perceived self-efficacy

Premature discontinuation of hormonal treatment/lack of treatment uptake

(Brotto, Yule & Brecken, 2010 Gilbert et al, Maturitas, 2010; Leung et al. 2016; Ribi et al, 2016)
Biopsychosocial Model

**Biologic**
- Hormonal alterations
- Change in body integrity, including scarring
- Loss of body part
- Lack of sensation
- Pain
- Fatigue
- Intervention: Medical consultation including gynecology, urology, sexual medicine, endocrinology, pelvic floor rehabilitation

**Psychological**
- Emotions (eg, depression, anxiety)
- Cognition (body image, negative thinking)
- Motivation (self-efficacy)
- Intervention: Psychiatry consult, individual counseling, cognitive-behavioral therapy, sex therapy techniques

**Interpersonal**
- Relationship discord
- Fear of intimacy
- Lack of communication
- Intervention: Couples therapy, supportive group counseling

**Social/Cultural**
- Religious beliefs
- Cultural values
- Social norms
- Intervention: Culturally sensitive educational materials, values clarification as part of assessment, integration of linguistic/cultural interpreters into multidisciplinary care team

*Cancer-related sexual problems*

*Cancer-related sexual problems*

*Bober SB & Varela VS, J Clin Oncol, 2012*
Body Image after Breast Cancer

• 50% - 75% younger survivors report problems with body image satisfaction

• Body image satisfaction is positively related to quality of life

• Body image is influenced by a multitude of factors, including **patient characteristics** and **adjuvant treatments** such as chemotherapy and/or radiation therapy, and type of reconstruction
  • Younger pts and pts with higher BMI report more distress related to body image
  • Immediate reconstruction & autologous tissue-based more favorable outcomes

Surgical Risk Factors: Conflicting Findings

• 2005 prospective survey of 549 survivors < age 50: Women with breast reconstruction were less satisfied with body image compared to no reconstruction.

• Self-report of 170 women post-surgery: Reconstruction pts. have better body image compared to breast conservation pts. but no psychological advantages of one type of treatment over another.

• 2016 cross-sectional study of 400 women (controls/ breast conservation, mast. no reconstruction, mast. with reconstruction): Women post-mast. with reconstruction had equivalent breast satisfaction to women with breast conservation. Both groups comparable to controls. No reconstruction had lowest satisfaction scores.

Personality traits, Interpersonal Experience and Cultural assumptions also influential

Vaginal Health: Vulvovaginal Atrophy

Estrogen deficiency → genitourinary symptoms that progress over time

- Vulvovaginal dryness
- Burning/Irritation
- Dyspareunia
- Urinary symptoms of urgency, dysuria or recurrent urinary tract infections

Recent chart review of 800 BR CA survivors: 60% of women with documented GSM symptoms did not receive any form of treatment or referrals for services

Cook et al, Menopause 2017; Faubion et al, Menopause 2018
Premature Menopause / Sexual Function

Study of 461 pre-menopausal survivors surveyed 1 yr post-dx: Sexual Interest and Sexual Function

• Treatment-induced amenorrhea associated with both decreased interest and decreased sexual function

• Women with treatment-induced amenorrhea reported worse dysfunction than both women who received chemotherapy but were not ammenorheic & women who did not receive chemo

*Rosenberg et al, Cancer, 2014*
And then...

Pain/ Vaginismus

Fear/Anxiety

Avoidance/ Decreased Sexual Activity

Decreased Sexual Desire/Arousal

Low Desire: most commonly reported sexual problem after breast cancer

Barni 1997; Brotto & Heiman, 2007; Burwell 2006; Jensen 2003; Fobair 2006
Identification and Assessment of symptoms

Communication about sexual health is hampered by perceived lack of available brief and effectual patient resources, including -

• Simple clinical checklists
• Educational materials
• Appropriate referral resources

Tsai, 2004; Bober, Reese, Barbera et al, 2016
Screening

Sexual Symptom Checklist For Women After Cancer

Please answer the following questions about your overall sexual function:

1. Are you satisfied with your sexual function?  ☐ Yes ☐ No
2. Do you have any concerns about vaginal health?  ☐ Yes ☐ No

If not satisfied with sexual function AND/OR concerns about vaginal health, please continue.

2. Do you experience any of the following sexual problems or concerns?
☐ Little or no interest in sex
☐ Decreased sensation (or loss of sensation)
☐ Decreased vaginal lubrication (dryness)
☐ Difficulty reaching orgasm
☐ Pain during sex
☐ Vaginal or vulvar pain or discomfort (not during sex)
☐ Anxiety about having sex
☐ Other Problem or Concern: __________________

[TIP: Some patients will respond that they are not having these problems or concerns because they stopped having sex altogether. The provider should reassure the patient, let her know that she is not alone, and ask if she can recall what kinds of problems or concerns she was having that led her to stop having sex.]

3. Would you like more information, resources, and/or would you like to speak with someone about these issues?
☐ Yes ☐ No

Female Sexual Quotient Questionnaire (FSQ)

The questionnaire is based upon the last six months of your sex life, rating your answers as follows:

- 0 or rarely
- 1 or 2 of the time
- 3 or 4 of the time
- 5 or 6
- 7 or 8
- 9 or 10

- Think spontaneously in sex, remember about it or imagine yourself in sexual intercourse?
- Am I sex enough for you to be in the mood to participate in a sexual intercourse?
- Do you still find me exciting during sexual intercourse?
- Is it hard for me to continue sexual intercourse?
- Do you have wet lubrication during sexual intercourse?
- As sexual as your partner's arousal increases, do you also feel more stimulated?
- Do you relax enough vagina to facilitate penetration of the penis?
- Do you feel pain during sexual intercourse when penis penetrates your vagina?
- Could your sexual relationship be more satisfying?
- Sexual satisfaction encourage you to enjoy sex more frequently?

Factor 50

x (01 + 02 + 03 + 04 + 05 + 06 +15 - 071 + 08 + 09 + 010), in which 0 = question.

Female Sexual Quotient Scoring:
82–100 (Highly satisfied): I am very sexually satisfied and enjoy my sex life to the maximum.
62–80 (Partially satisfied): I enjoy sex, but there is some room for improvement.
42–60 (Average): I am concerned that my sexual enjoyment really could be better.
22–40 (Slight dissatisfaction): I feel that my sex life does not give me enough satisfaction.
0–20 (Highly dissatisfied): I am very concerned that I don’t get any satisfaction from my sex life.

Or Just Ask...

- "Many of my patients have questions about how sexual function is impacted by treatment. Do you have any concerns that you’d like to ask about?"

- “It is very common to have changes in sexual function after breast cancer diagnosis. Is this something you would like help with?”

- “Many women who have menopausal symptoms also have concerns about sexual function. What about you?"
Treatment and Recovery

- Sexual Health
- General Health

- Emotion
- Cognition
- Motivation

- Previous
- Current

- Norms
- Expectations

Physical

Mental

Social

Cultural
## Treatment: Pharmacologic

<table>
<thead>
<tr>
<th>Treatment for VVA</th>
<th>Specific Therapy/Use</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vaginal Estrogen</td>
<td>Local (not systemic) therapy</td>
</tr>
<tr>
<td></td>
<td>Tablet/ring/cream</td>
</tr>
<tr>
<td>Vaginal DHEA</td>
<td>Intravaginal ovules (prasterone)</td>
</tr>
<tr>
<td>Lidocaine</td>
<td>For insertional pain. Topical application to vestibule (4% aqueous lidocaine) before sexual activity</td>
</tr>
<tr>
<td>Off-label vaginal testosterone</td>
<td>Controversial</td>
</tr>
<tr>
<td>Off-label fractional CO₂ laser</td>
<td>No evidence-base for use after BR CA</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Treatment for Low Desire</th>
<th>Mechanism of Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>Flibanserin (daily use at bedtime)</td>
<td>5-HT1A serotonin receptor agonist and 5-HT2A receptor antagonist</td>
</tr>
<tr>
<td>Bremalanotide (on-demand use)</td>
<td>Melanocortin 1 &amp; 4 receptor agonist</td>
</tr>
</tbody>
</table>

Adapted from Faubion et al, Menopause, 2018
Behavioral Interventions

• Growing evidence-base for behavioral intervention regarding sexual function
  ◦ Mindfulness-based therapy
  ◦ Cognitive-behavioral Therapy / Mindfulness-based Cognitive Therapy
  ◦ Couples-based intimacy enhancement
  ◦ Psychoeductional approaches

• Recent internet-based RCT: CBT for BR CA survivors with sexual dysfunction led to improvement in overall sexual functioning, including desire, arousal, and vaginal lubrication.
  - 24 weeks, therapist-guided sessions using telephone-platform
  - Successful but resource and time-intensive

Hummel et al, JCO, 2017. Reese et al, Psychooncology, 2018
SHARE-OS (Sexual Health and Rehabilitation After Ovarian Suppression)

Aim: Develop & test brief, sexual health intervention to reduce sexual dysfunction & distress for young breast cancer survivors currently on ovarian suppression.

- **Brief**: Ease of access and dissemination
- **Concentrated**: Content both didactic and experiential
- **Theory-driven**: *Self-Determination Theory* (Competence, Connection, Autonomy) / *Mindfulness-based sexual rehabilitation therapy* (intention, attention, non-judging awareness)
- **Group Format**: Group session paired with individual tailoring
START-OC: Intervention Overview

- **Single half-day group intervention**
  Didactic & Experiential
  Patient education materials/resources

- **Individualized action plan**
  Choose problem(s) and next steps

- **Brief telephone follow-up (+ one month)**
  Review of action plan
  Additional support offered if needed
Intervention Content: An Integrative Approach

• Module 1 – **Targeted sexual health education**
  Includes education about vaginal health, strategies for enhancing arousal/desire and focus on how to communicate about symptoms

• Module 2- **Body awareness (pelvic floor)/Relaxation Training**
  Pelvic floor education, progressive muscle relaxation, body scan exercise

• Module 3- **Mindfulness-Based Exercise**
  Increase non-judging awareness of automatic thoughts; moving from avoidance/distraction to awareness and acceptance

• Module 4- **Personalized Goal-setting / Action-planning**
Sexual Health: Challenges and Future Directions

- Research to date primarily descriptive; qualitative/survey data
- Also limited knowledge re diverse/underserved populations
- What is the optimal timing of intervention for young survivors?
- What are optimal methods for intervention delivery? On-line? In-person? Group versus couples versus individual?
- How do we tailor or target appropriately?
- Who delivers this information? Training? Mid-level?
- What is the role of technology in this kind of care?
“It is a waste to be alive but not to live fully”, BR CA survivor, age 38