Body image and sexuality issues after surgery or cancer

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June 26, 2010
Why doesn’t sex get talked about?

- Culture saturated with sexy images, but frank conversation about real sex not encouraged
- People feel anxious about it
- Lots of misinformation
- Challenges in how to communicate
- It can feel embarrassing, shameful
- Clinicians often aren’t sure how what to say if patient endorses a problem (Pandora’s box)
Sexual Health and Quality of Life

- Sexuality is a fundamental, life-affirming element of the human experience across the lifespan.

- Sex is multi-dimensional: physiology, behavior, emotion, cognition, body image, self-esteem.

- Sexuality is a relational experience.

- Sexuality has different meanings and levels of importance to each individual; wide and varied range of normal functioning.
Beyond a narrow definition...

- Sexuality is NOT just intercourse or a physical encounter that ends with orgasm
- Sexuality is an experience that shifts in meaning and practice across time
- Intimacy is life-affirming; can ease anxiety, release stress, maintain sense of connection and help with experience of recovery
Sexuality: Always within a Context

- **Culture/religion** (what is taboo?)
- **Age** (if older, does sexuality still matter?)
- **Gender** (comfort with opposite sex pt?)
- **Socio-economic level** (class assumptions?)
- **Sexual Orientation** (discomfort in taking history?)
- **Status** (what if single, widowed, unpartnered?)
Sexuality and Cancer/Surgery

- Sexual dysfunction is one of the most common, enduring consequence of cancer treatment and risk-reduction surgery.

- Sex is often one of the first aspects of “normal” life to be disrupted.

- Many survivors/previvors say they were not fully prepared for dealing with changes in sex life.
How common is it?

• 50% - 96% of BC survivors report at least one major, long-lasting sexual or reproductive health problem (Ganz 1998, 1999)

• 74-95% of women after GYN cancers report severe, long-lasting sexual problems (Ganz, 1998, 1999).

• Many “Previvors” report disruptions in sexuality and body image but get little attention because they don’t have cancer (Matloff, Barnett & Bober, 2009)
“Well, you look great…”

- “I feel like I have been neutered. Like I am not a real woman anymore.” (age 41)

- “I feel like a talking head, just completely disconnected from everything below the neck.” (age 47)

- “Of course I am grateful to be alive, but I just don’t feel much; just flat. I’m not really interested in sex anymore.” (age 53)

- “No one asked me about it, but they assumed I’m not having sex because I’m widowed.” (age 68)
Sexual Rehabilitation is neither routinely offered nor provided in the vast majority of oncology treatment settings.
Impact on Sexuality/Body Image

• Sexuality is directly impacted by range of treatments for cancer and cancer risk reduction
  – Surgery
  – Radiation
  – Chemotherapy
  – Adjuvant hormonal therapy
Most Common Problems...

- Changes in body image & self-esteem
- Premature menopause
- Pain (discomfort with penetration)
- Decreased physical response, arousal
- Difficulty reaching orgasm
- Decreased interest & low desire
Who is at Increased Risk?

- Women with previous sexual problems
- Younger Women (20’s and 30’s)
- Women who experiencing depression or anxiety
- Women dealing with relationship difficulties
- Women who are not in partnered during time of diagnosis/treatment
Self-Esteem and Body Image

- Body image and sexual issues may become increasingly more pressing over time (Graziottin, 2006).

- Body image issues greatest in woman with:
  - Advanced cancer
  - Lymphedema
  - Decreased physical vitality (more sedentary)
  - Poor social support/ lack of current relationship
Body Change and Body Image

• Scars, skin changes, surgical reconstruction (“visible”)

• Loss of body parts, loss of limbs, loss of sensation (“invisible” or hidden)

• Body weight change

• Changes in physical ability/fatigue

• Feeling flawed, unattractive → self-esteem

• Changes are hard to talk about: shame, embarrassment, guilt

• Desire/Libido directly impacted by above
Disrupted Ovarian Functioning: Premature Menopause

- Impairment of ovarian functioning results in abrupt loss of estrogen
  - Chemotherapy-induced (adjuvant tx for br ca)
  - Surgically-induced (oophorectomy)
  - Hormonal (Tam/Aromatase inhibitors)

- Majority of women > 35 stay in menopause after chemotherapy treatment

- Sudden, early menopause can be dramatic; problems often last after treatment ends
Menopausal Symptoms and Sexual Functioning

- Hot flashes,
- Vaginal dryness, burning, itching → Pain
- Decreased Arousal
- Difficulty Reaching Orgasm
- Some women have low androgen levels which may be related to decreases in desire and pleasure
- Fertility-related distress

(Schover, 2000, Partridge 2004, 2008)
Primary Issue: Vaginal Dryness

- Lack of estrogen leads to vaginal dryness and tightness (vaginal atrophy), tissue becomes thin
- Loss of stretch in the vaginal tissues can make penetration painful, burning
- Painful sex: why keep trying?
- Leads to vaginismus – pain cycle
- Not just about sex: e.g., pain during pelvic examinations
Tamoxifen and Aromatase Inhibitors

- Tamoxifen → Hot Flashes, Vaginal discharge, Vaginal tightness, Discomfort with intercourse

- Mixed results re Sexual Functioning
  - Some studies find no change in functioning. One larger study: 54% of women reported pain with intercourse and vaginal dryness

- AIs → Similar profile regarding menopausal symptoms. More vaginal dryness than Tam (Buijs et al, 2008; Cella & Fallowfield, 2008)
Now What?
“Integrative Model of Renewal”

Track 1: Focus on Self
• Restoring sexual health is related to restoring overall health and well-being
  – Vaginal and sexual health in context of whole body health
  – Lifestyle and behavior changes that a woman can embrace by herself, for herself
  – Opportunity to explore individual thoughts and feelings related to body image, self-esteem and self-efficacy
Track Two...

Track 2: Focus on relationship

- Restoring sexuality in social/relational context
  - Understand sexual history, previous norms for communication, past/current expectations
  - Plan for incorporating partner into counseling
    - Couple-focused communication strategies
    - Sensate Focus – modifiable as needed
Elements of Integrative Model

• Information/Education
• Body Awareness, Physical Attunement
• Cognitive-Behavioral Intervention
• Social Support
Information: Managing Menopause

• Vaginal Dryness → Pain
  – First line: Use vaginal moisturizers and lubricants
    • Water-based or Silicone, Glycerin-free, perfume-free
    • Be cautious of “warming” lubricants
    • Vaginal Moisturizers such as Replens, Vitamin E oil
  – Second Line: Possible use of vaginal estrogen
    • Estring – vaginal ring stays intact up to 3 months
    • Vagifem - tablet that sticks to vaginal wall
    • Estrace – vaginal cream
Managing Pain

• The pelvic floor is innervated by the limbic system and highly reactive to emotional stimuli
  – Pelvic Floor Therapies very helpful for pain
• Learned Relaxation of the pelvic floor
• Muscles Toning Devices
• Kegel Exercises
• Pelvic PT
• Current RCT examining PF relaxation with Replens and olive oil lubricant *(Mok et al)*
Vaginal Dilation

- Mechanical stretching of tissue may increase elasticity
- Need to use Dilators with proper lubrication
- Allows woman to regain sense of control
- Specifically indicated when woman has developed vaginismus – or any muscle-clenching reaction triggered by pain/fear
Restoring Vaginal Health...

- Restoring vaginal health after menopause requires an increase of blood flow to vaginal tissue.
- Small Clitoral vacuum pump designed to increase genital blood flow—approved by FDA.
- RCT to show EROS had a positive effect on desire, arousal,orgasmic satisfaction and sexual distress (Brotto et al, 2008).
Body Attunement: Coping with Changes in Arousal and Orgasm

• Emphasis on integrating mind and body
  – Rediscovery of pleasure, sensation in body post br-ca

• Stepping outside of old habits...
  – Typically women need increased intensity and duration of stimulation (especially clitoral)

• Value of relaxation/mindfulness/attunement
  – Body scan, progressive muscle relaxation

• Use of self-touch, vibrators
Low Desire

- Stress of illness
- Fatigue
- Sadness / Depression
- Relationship issues made worse by illness
- Body image changes, feeling unattractive
- Painful sex
- Medication side effects
Can I ever get my groove back??
Good news!

- Acknowledging change/Accepting loss
- Opportunity to chart new course
- Opportunity to expand one’s repertoire
- Critical to shift focus to pleasure and sensuality, away from “sex” only
Thinking affects Desire

• Use of structured cognitive tasks
  – Cognitive Restructuring
  – Cognitive Cueing: Recognizing sexual thoughts - keeping a “Desire Diary”
  – Guided imagery, mindfulness
  – Relaxation exercises/Body Awareness
  – Using erotica: reading, video, fantasies
Focus on Behavior....

- Re-focus on Pleasure and Sensuality
  - Begin slowly – Make a plan
  - Sensate Focus exercises

- Lifestyle changes
  - Exercise, physical activity
  - Stress management
  - Relaxation
Sexual Health Program
LAF Survivorship Clinic

Mission: To help patients restore healthy sexual functioning as an integral part of overall survivorship care.

The SHP is a multi-disciplinary clinic that incorporates medical and behavioral approaches to successfully treat sexual dysfunction after cancer. The SHP aims to develop, evaluate and disseminate practical programs of sexual rehabilitation for a wide range of cancer survivors.