Women's Sexual Health after Transplant

Celebrating a Second Chance at Life Survivorship Symposium

July 11-17, 2020

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Women’s Sexual Health after Transplant

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Overview

- What is sexual health and how is it related to quality of life
- Common sexual health side effects that effect women after BMT
- How to think about sexual rehabilitation using biopsychosocial model
- Strategies for sexual rehabilitation after BMT: resources and support
Sexuality/Sexual Health

- A fundamental / life-affirming element of human experience across the lifespan

- A multi-dimensional experience: physiology, behavior, emotion, cognition, identity
  NOT just sexual intercourse

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Values

Body Image

Culture

Social

Past History

Sexuality

Mental Health

General Health
Chasing Normal...

• Wide and varied range of “normal” sexual function

• Different meanings and levels of importance to each individual

Key Point: If changes with sexual health are **distressing** or **bothersome to you**, then this aspect of care deserves attention!
As recognized by World Health Organization: Sexual health is a fundamental human right

Sexual health is directly related to quality of life (QOL)

Unaddressed sexual problems are associated with increased anxiety, depression, and relationship stress
Sexual health after BMT

- Sexual health often one of the first aspects of “normal” life to be disrupted after diagnosis and treatment.

- Changes in intimacy/sexual function are among most common, distressing long-term consequences of BMT.

- Women report being “not fully prepared” for dealing with changes in sexual function.
“When it came to sex, I didn’t hear much about it…”

- Culture saturated with graphic images but lack of frank conversation about real sex in most medical settings
- Misinformation/ Unrealistic Assumptions / Taboos
- Providers often aren’t sure what to say if patients asks about/acknowledges a problem about sexual health
Most Common Changes in Sexual Health post-BMT

Changes regarding sexual response
- Arousal
- Changes in vaginal health (e.g., loss of lubrication)
- Orgasmic dysfunction
- Chronic sexual discomfort/pain

Changes in sexual desire and sexual motivation
- Low sexual desire / Reduced sexual motivation
- Decreased body image, loss of sexual self-esteem

Vaginal GVHD
Women at Increased Risk?

- Women with previous sexual problems
- Younger women (premenopausal before treatment)
- Women with history of depression or anxiety
- Women with relationship difficulties/stress previously
- Women who are not partnered during time of diagnosis/treatment
Changes Related to Disrupted Ovarian Function

- Chemotherapy-induced
- Radiation-induced

Vaginal Changes: ↓ Blood Supply, Glycogen, changes in pH
  - vaginal length and diameter
  - lubrication
  - elasticity
  - sexual pain
  - inflammation, infection

Vulvar Changes: ↓ Collagen, Adipose tissue

↓ Testosterone (50% of T made produced by ovaries)
Vaginal Health: What Women Need to Know

- Moisture
- Stretch
- Bloodflow
Moisture

• First line: Vaginal moisturizers & lubricants
  • Learn about vaginal moisturizers (3-5x week as needed)- also need to balance pH
  • Lubricants: Water-based/Silicone, Glycerin-free, perfume-free
  • Coconut oil for perineum/ perineal massage

• Second Line: Possible use of vaginal estrogen / local hormonal tx
  • Estring – vaginal ring stays intact up to 3 months
  • Vagifem/ Imvexxy - vaginal inserts that deliver local estrogen
  • Estrace – vaginal cream
  • Intrarosa – plant-derived form of DHEA (vaginal insert)
Stretch

- Learning about **pelvic floor/ pf rehabilitation**
  - Pelvic Floor Relaxation Therapy
  - Muscle Toning (when appropriate)
  - Pelvic floor innervated by limbic system

- Strategies such as vaginal dilator therapy
- Myofascial trigger point release
- Pelvic floor PT
Bloodflow

- Enhancing vaginal health by increasing blood flow to genital tissue
- Small Clitoral vacuum pump designed to increased genital blood flow – approved by FDA
- RCT to show EROS had positive effect on desire, arousal, orgasmic satisfaction and sexual distress
Loss of Desire: A Multiple Factorial Experience

Changes in Function & Hormones

Changes in Body Integrity

Vigilance
Anxiety
Avoidance

Changes in Body Image

Alternatively: we can learn to cope with change
Vaginal GVH

- GVHD of the vulva and vagina happens when the donor cells attack these tissues. Most commonly happens within a year after transplant.


- Symptoms comparable to genito-urinary symptoms of menopause – need to be diagnosed by GYN

- Treatment may include topical steroids and/or topical immunosuppressants
Next Steps:
A Framework for Sexual Health & Renewal

- Social & Cultural
- Religion
- History
- Current/Future
- Emotion
- Cognition
- Motivation
- Sexual Health
- General Health
- Physical
- Mental
- Social
- Cultural

Bober & Varela, JCO, 2012
Starting with Physical Health and Body Integrity

Sexual health as part of overall health & well-being

- Identify & address the “mechanics” (e.g., pain, dryness)
- Support lifestyle/behavior change (e.g. sleep, exercise, diet)
- Address relevant medical factors (e.g., anti-depressants, changes in mobility/anatomy/physical function)
Being in the Body without Anxiety...

• Acknowledge changes (including accepting potential loss)

• Focus on strength and endurance: Appreciating your body for getting to the present moment

• Getting active also improves body image. (walking, yoga, dance, weight-training...)

• Shift attention to something that you like...

• Commit to keeping an open mind
Tuning In and Talking Back...

• Notice how avoidance/distraction “protects” from anxiety
  • Practice tuning into one part of your body or physical experience and don’t DO anything.... What happens? What comes to mind?

• Notice when you “tune in”, it may feel like someone hit “play” on the “judgment tape loop” ...
  • But this time: practice talking back to those thoughts, as if you were gently challenging a friend...
  • Intensity of thought... does not make them true
  • Thoughts are just that...
Relationships

• Dating/Disclosure

• Communicating about expectations/understanding

• Educating partners about what’s going on…

• Knowing when you might need more support
Common Concern: Low Desire

- Desire does not need to be spontaneous
- Attention
- Intention
- Curiosity
- Commitment
PLEASURE, Not PRESSURE

• Don’t have to have a perfect body give/receive pleasure!

• If you have feel self-conscious about something, get creative and work around it!

• Take your time and get to know what feels good for you...

• Think about the process of discovering what feels pleasurable rather than being goal-oriented only
From Spontaneity to Intention... Cultivating Desire

• Desire shifts from a spontaneous experience to one that is cultivated

• Cultivate desire by focusing on pleasure and sensuality
  • Begin slowly – Make a plan
  • Genital self-exploration/Self-touch
  • Take the pressure off...

• Lifestyle changes
  • Exercise/Physical activity
  • Stress management/Relaxation
  • Mindfulness
Acknowledging Change, Loss & Opportunity

• Acknowledge change/Get creative

• Embrace opportunity to chart new course

• Appreciate opportunity to expand one’s repertoire

• Learn to shift focus to pleasure and sensuality

• Choose to be optimistic and get active!
Education, Resources & Support

Written materials (hard copy and/or web-based) by ACS (Sexuality and Cancer), NCI, www.dana-farber.org/adult-survivorship-program/

Biblio-therapy (e.g., L Schover, A Katz, S Kydd,) YouTube

Finding the right team (counseling, PT, GYN etc)

Sexual Rehab Counseling (couple, individual)

Locating personal products and using them
Questions?

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