

ECHO IDAHO

Cancer Survivorship

Supporting Sexual Health and Self-Image in Cancer Survivorship

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None of the planners or presenters for this educational activity have relevant financial relationship(s) to disclose with ineligible companies whose primary business is producing, marketing, selling, re-selling, or distributing healthcare products used by or on patients.

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Professions



Disclosures

- Regretfully, I have no financial conflict to disclose.

Learning Objectives

- ▶ 20 minutes presentation, 10-minute Q&A at end
- ▶ Describe prevalence of and types of sexual problems experienced by those in treatment for different types of cancer
- ▶ Describe care management strategies to improve the physical, emotional, and sexual wellbeing of individuals and couples in treatment for cancer
- ▶ Identify strategies for provider and patient with sexual concerns related to cancer treatment

- Objective 1

Describe prevalence of and types of sexual problems experienced by those in treatment for different types of cancer



Sexual Impact:

Sexual functioning and satisfaction ranked THIRD most frequently reported physical concern

- “a lot” 29%
- “a little” 37%
- less than half received medical care for concern

Survivors expressed significant emotional concerns related to sexual health (% rated as a lot/a little):

- Sadness and depression
- Personal appearance
- Stigma
- Personal relationships

• Livestrong Survivor Survey Final Report.2010. Available at: https://d1un1nybq8gi3x.cloudfront.net/sites/default/files/what-we-do/reports/LSSurvivorSurveyReport_final_0.pdf. Accessed May 2017

WHY REPORTED FOR ALL CANCERS?

- ▶ Sexual Health concerns across all cancers
 - ▶ **60% in women (1)**
 - ▶ **80% in men (2)**
- ▶ Breast cancer:
 - ▶ up to 90% (2)
- ▶ Gynecologic cancer:
 - ▶ 78.4% (1)
- ▶ Non-Hodgkins Lymphoma
 - ▶ Up to 64% in women, 49% in men (3)
- ▶ Prostate cancer
 - ▶ 40-82% with localized disease (4,5)
- ▶ Rectal cancer
 - ▶ 70-80% in men; 30-45% in women (6,7)
- ▶ HSCT recipients
 - ▶ 51% in men, 66% in women (8)

▶ 1. Majorino MI, *et al.*, Endocrine 2016; 54:329-41; 2. Avery JC, *et al.*, J GI Oncol 2014; 5:388-94;
3. Kim JR, *et al.*, Ann Hematol 2017; 96:739-47; 4. Wortel RC, *et al.*, J Sex Med 2016; 13:1695-1703;
5. Bessaoud F, *et al.*, Bull Cancer 2016; 10:829-40; 6. Saito S, *et al.*, Eur J Surg Oncol 2016; 42:1851-58;
7. Gilbert A, *et al.*, Int J Rad Onc Biol Phys 2015; 92:555-67; 8. Dyer G, *et al.*, Br J Haematol 2016; 172:592-601.



Global Impact

ANY SURGERY OR RADIATION TO THE PELVIS MAY RESULT IN SEXUAL DIFFICULTIES

ANY SURGERY OR RADIATION TO THE BRAIN MAY RESULT IN SEXUAL DIFFICULTIES

Sexual Side Effects: breast



Surgery

- Global changes (Ussher Perz Gilbert 2012)
- Loss of sexual identity and feeling less attractive (Fallbjork 2012)
- Lymphedema (Winch 2015)
- Reconstruction may mitigate losses (Duggal 2013)
- Prophylactic mastectomy on contralateral side creates unanticipated sexual changes (Lee 2013)
- Breast specific sensuality (Gass 2017)

Radiation

- Adjuvant to lumpectomy or mastectomy
- Fatigue
- Skin damage
- Competing demands
- Length of treatment

Chemotherapy

- Ovarian shut down
- Hair loss
- Vulva-vaginal atrophy (Lester 2015)
- Dyspareunia (Boquiren 2016)
- Loss of libido
- Sexual distress may be less in women who are not partnered (Raggio 2014)
- Weight gain (Brunet 2013)
- Incontinence

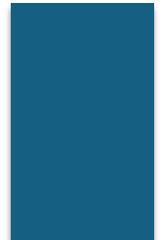
Sexual Side Effects: male pelvis

Radical Prostatectomy

- Immediate ED
- Penile Shrinkage
- Peyronie's Disease
- Incontinence with arousal or orgasm
- Dysorgasmia
- Dry Orgasm

Radiation

- Venous Leak
- Gradual ED Onset
- Genital Shrinkage
- Dysorgasmia
- Decrease in ejaculation



Sexual Side Effects: female pelvis

Pain

Loss of sensation and sensitivity

Loss of libido

Vulvo-vaginal dryness (Sadovsky 2010)

Sexual activity decreased (41% vs 78%; younger women more impacted)(Grimm 2015)

Radiation adds effects – fatigue, skin damage, vaginal discharge (Rodrigues 2012)

Radiation – internal +/- external

Vulvo-vaginal atrophy

Sensitivity to partner's semen (Rai 2014)

Narrow and shortened vagina (Pieterse 2013)

Association of sexual activity with development of cancer (HPV- related) (Aerts 2012)

Colorectal Interventions

- ▶ Dyspareunia
- ▶ Problems worse with rectal cancer (Den Oudsten 2012)
- ▶ Women experience decreased enjoyment (Leon-Carlyle 2015)
- ▶ Sexual activity decreases
 - 50% of women before surgery to 35% after (Traa 2014)
- ▶ Significant impact for those who engage in anal play/penetration
- ▶ Multi-modality treatment usual
- ▶ Challenge for anal play/intercourse
- ▶ Concerns about ostomy
 - ▶ Leakage, odors, gas, noises (Neuman 2011)
 - ▶ 86% of women reported at least one problem related to body image and 81% reported significant sexual dysfunction (Benedict 2016)
- ▶ Stoma appears red and moist and may bleed periodically
- ▶ Response shift may occur (stoma better than death) (Neuman 2012)
- ▶ Women: alternative positions for intercourse : dilators to prevent adhesions
- ▶ Psycho-education improves couple communication (Reese 2014) and exploration of non-coital activities (Perz 2015)
- ▶ Referral to ostomy therapist/nurse



- Objective 2

Describe care management strategies to improve the physical, emotional, and sexual wellbeing of individuals and couples in treatment for cancer



Areas of treatment: TEAM approach

Physical
/Biological

Personal /
Emotional Self

Social /
Relationships

Do you know how to treat, or who to ask?

- Loss of sexual libido
- Loss of sexual sensation
- Sexual pain
- Permanent ED
- Vulvo-vaginal atrophy
- Clitoral adhesions
- Vaginal stenosis
- Loss of identity
- Depression
- Lymphedema
- Skin concerns
- Hair loss
- Weight gain
- Orgasm difficulty



Vulva-Vaginal Dryness and Pain

Biological concerns

- ▶ Adjuvant endocrine therapy in breast cancer
- ▶ Tamoxifen is mildly estrogenic to vaginal tissues (Rogers & Kristjanson 2002)
- ▶ Aromatase Inhibitors have severe effects on vulva and vagina (Bentrem & Jordan 2002)
- ▶ Sexual dysfunction common (Schover et al 2014)
 - ▶ 93% meet definition and 75% distressed about this
 - ▶ At baseline just 52% were sexually active but 79% developed new sexual problem
 - ▶ 24% stopped having sex
 - ▶ 13% changed medication
- ▶ Testosterone is not FDA-approved
- ▶ Radiation causes vaginal stenosis

Interventions for Vulva-Vaginal Dryness and Pain

biological concerns

- ▶ Low dose estriol or estradiol (Dodders, 2019)
- ▶ Conjugated equine estrogen cream (Faubion, 2018)
- ▶ Local estrogen safer for women on tamoxifen than AI (Faubion, 2018)
- ▶ Meta-analysis showed that local E is safe (Pavlovic, 2019)
- ▶ Aqueous lidocaine 4% (Goetsch, 2014)
- ▶ Ospemifine and DHEA (Lemke, 2017)
- ▶ Dilators to prevent stenosis
 - ▶ Resistance (Cullen 2013; Rinske 2015)
- ▶ Mindfulness training
- ▶ Moisturizers and Lubricants (NO OILS)

Body Image Concerns

- ▶ Worse for younger women (Paterson, 2016)
- ▶ Immediate reconstruction may help but...
 - ▶ Disappointment (Hart 2015)
 - ▶ Loss of breast sensuality (Gass 2017)
- ▶ Weight gain
- ▶ Relationship to pre-treatment body image (Falk & Dahl, 2010)
- ▶ Affects women after cancer treatment
 - ▶ feeling empty
 - ▶ presence of scars (Rowlands 2014)



OUR DEFINITION OF
“SEXY”

MUST CONTINUE TO
EXPAND IN A WAY THAT CAN
ALWAYS INCLUDE
OURSELVES

Impact on Relationship(s) Relational Concerns

- ▶ Couple based sex therapy (Carroll 2016)
 - ▶ Sensate focus
 - ▶ Coping and attachment
 - ▶ Emotion focused therapy
- ▶ Couple-based Intimacy Enhancement Intervention (Barsky Reese 2016)
- ▶ Psychoeducational interventions increase satisfaction with sexual function and decreased sexual bother (Lassen et al, 2013)
- ▶ Encouraging survivors and partners to mourn the loss of sexual functioning important for both women (Pillai-Friedman & Ashline 2014) and men (Wittman 2009)

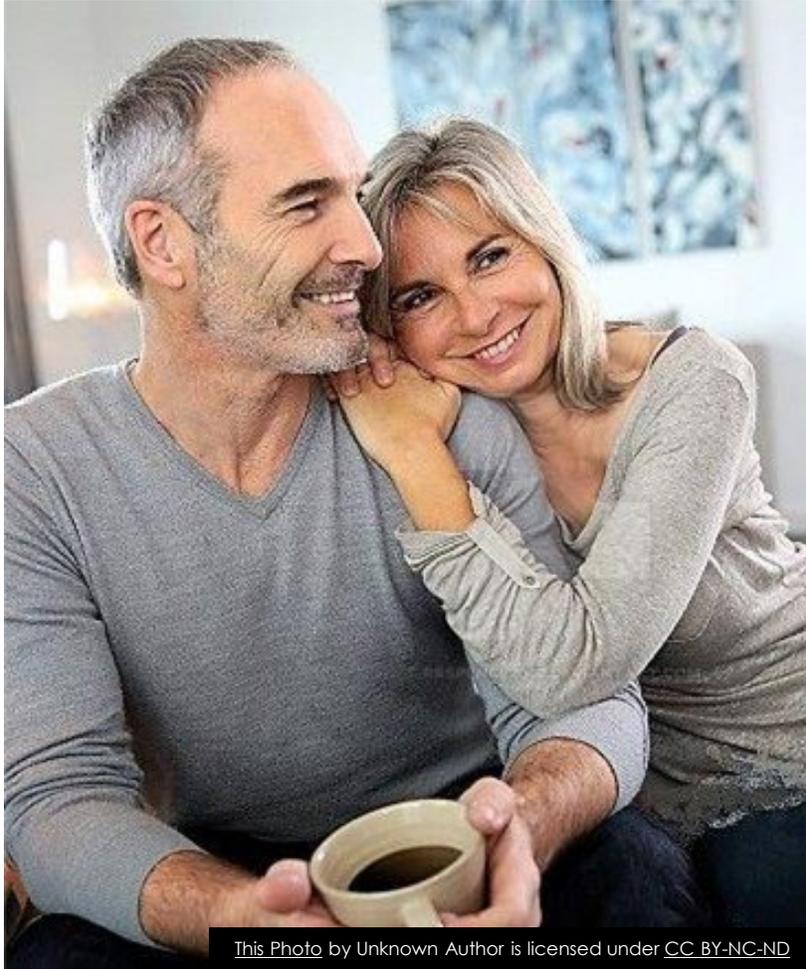


- Objective 3
Identify strategies for provider and patient with sexual concerns related to cancer treatment



Send a Hopeful Message

- ▶ Pleasure and Connection are not dependent on penetration
- ▶ An orgasm is not dependent on an erection
- ▶ An orgasm is not dependent on a prostate
- ▶ An orgasm is not dependent on ejaculation
- ▶ There is more to sex than intercourse
- ▶ Sexual Pleasure and connection can be developed, improved, and sustained despite the impacts of cancer
- ▶ Refer to Sex Therapists in your area



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Re-defining Sex

*CONNECTION AND PLEASURE

*REDEFINING SUCCESSFUL SEXUAL ENCOUNTER

*OUR DEFINITION OF SEXY MUST CONTINUE TO EXPAND IN A WAY THAT CAN ALWAYS INCLUDE OURSELVES

Sexuality is not confined to penile & vaginal intercourse



- ▶ Intimacy
- ▶ Sensuality
- ▶ Body image
- ▶ Arousal
- ▶ Desire
- ▶ Climax
- ▶ Satisfaction



Non-penetrative Sex

- ▶ Degree of grieving the loss of something that was enjoyable, reliable, easy
- ▶ Degree of tolerating what it's like to try something new – unsure of outcome
- ▶ Degree of “us against it” or collaborative spirit
- ▶ Sexual closeness not defined by penetration
- ▶ Sexual orgasm not defined by penetration
- ▶ Hands, mouths, tools, toys

Tools

Dialators

Oh Nuts

Vibrators

Fleshlight massagers

Lube



Validated Sexual Health Questionnaires

- ▶ Men
 - UCLA-PCI (20 item)
- ▶ Women
 - EPIC (50 items)
- ▶ SAQ (14 items)
- ▶ Sexual Function – Vaginal Changes questionnaire (20 items)
- ▶ EORTC QLQ-C30
- ▶ PROMIS
- ▶ SexFS (79 items in 11 domains)



EDUCATION IS KEY

- Explore sexual health is a concept beyond intercourse.
- Re-examine what it means to be “sexual”
- Normalise their experience
- Encourage communication between partners

RECOGNISE IN YOURSELF:

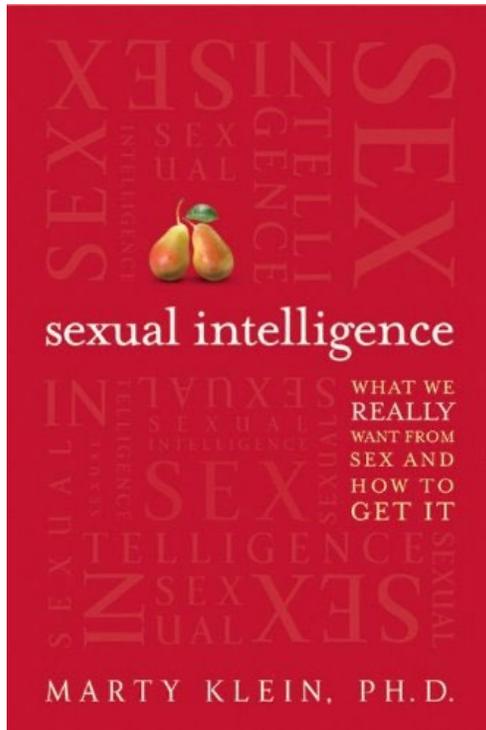
- Your own personal comfort zone
- Your own sexual self-schema



Office Resources

Book Recommendations

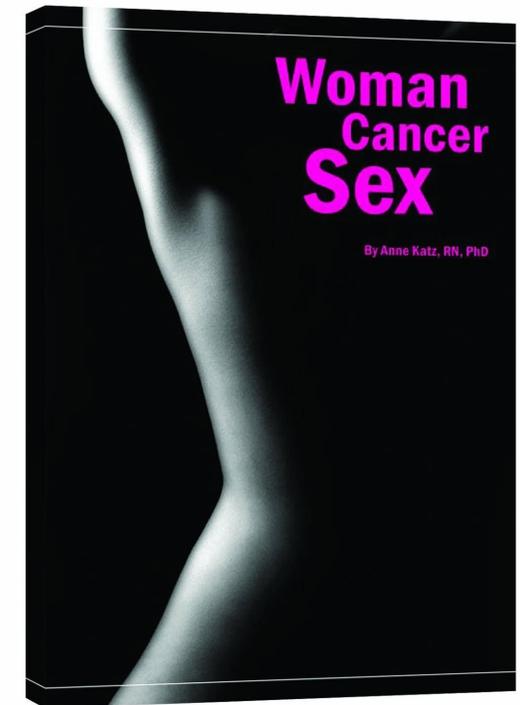
Sexual Intelligence



Men, Cancer, Sex Anne Katz



Women, Cancer, Sex



Let's keep in touch

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The mission of the Idaho Association of Sexual Health Professionals (ISHP) is to raise awareness and competency around sexual health matters in the Idaho community. The fulfillment of this mission lies within our five key areas of focus

- We hope to create networks and communities among multidisciplinary sexual health professionals.
- We commit to offer resources and referrals to the community members.
- We will work to provide best practice and medically accurate continuing education to Idaho professionals who work with clients and patients about sexual concerns, functioning, expression, and education.
- We exist to advocate for sexual health in Idaho legislation.
- We work to promote and protect the profession.

