Cancer and Sexual Health
Cancer and Sexual Health

Agenda

- Sexuality Definitions
- Patient’s Journey Through Cancer
- Common Side Effects
- Female Side Effects/Veronika Kolder, MD
- Male Side Effects/Brad Erickson, MD
- Distress Tool Screening
- Partner Relationship Challenges
- Points To Remember
Sensuality

Awareness and feeling about your own and other people’s bodies.

Enables us to feel good about how our bodies look and feel and what they can do.
Intimacy

The ability to be emotionally close to another human being and to accept closeness in return.
Sexual Identity

A person’s understanding of who she/he is sexually, including the sense of being male or of being female.

Sexual Identity consists of 3 interlocking pieces that together, affect how each person sees him/herself:

- Gender identity
- Gender role
- Sexual orientation
Sexual Health and Reproduction

A person’s capacity to reproduce
The behaviors and attitudes that make sexual relationships healthy and enjoyable
Sexualization

Ways in which people behave sexually to influence, manipulate, or control other people.
Sensuality

Sexual Identity

Intimacy

Sexualization

Sexual Health And Reproduction

Values

Awareness, acceptance of and comfort with one's own body; physiological and psychological enjoyment of one's own body and the bodies of others.

The use of sexuality to influence, control or manipulate others.

The ability and need to experience emotional closeness to another human being and have it returned.

Attitudes and behaviors related to producing children, care and maintenance of the sex and reproductive organs, and health consequences of sexual behavior.

The development of a sense of who one is sexually, including a sense of maleness and femaleness.
Personal Cancer Journey

AFTER CANCER
Solutions for Sexual Health

CANCER
vulnerable connection treatment pain
chemo shock betrayal doctors
confusion testing patient
therapy

survivor disease causes lost perspective cure
nurses support malignant
emotional mortality radiation families
In 2014:

**United States**
- 14.5 million cancer survivors

**Iowa**
- 142,870 cancer survivors
- 6,400 people will die annually
- 17,630 newly diagnosed
- 40-100% sexual dysfunction
Common Sexual Health Concerns From Cancer Treatments

**Painful Intercourse for women - 50%**
- Vaginal dryness/shortening/scarring

**Erectile Dysfunction for men**
(Men viewed decrease in sexual activity more negatively than women)

**Lack of Interest/energy**
- worry/fatigue 43%/depression/pain

**Altered Body Image**
- Organ Loss/Scarring
- Hair loss/weight gain
  (Feeling less attractive was considered more important than frequency of sexual activity for women)

**How to Communicate About Issues**
- How to Initiate conversations /find intimacy
Cancer Treatment
SURGERY

SIDE EFFECTS
• Loss of limb
• Structural changes
• Nerve damage

PROBLEM / SYMPTOM
• Altered Body Image
• Erectile Dysfunction
• Slow or dry orgasms
• Loss of sensitivity
• Incontinence

J Sex Med 2010;7:349-373, Cancer and Sexual Problems
Cancer Treatment
CHEMOTHERAPY

SIDE EFFECTS

• Loss of hair
• Weight gain/loss
• Nausea
• Loss of estrogen
• Vaginal dryness
• Loss of vaginal elasticity
• Hot flashes
• Shrinking/thinning of vagina
• Lower testosterone production in men

PROBLEM / SYMPTOM

• Altered Body Image
• Painful Intercourse
• Loss of libido
• Mood swings
• Irritability
• Urinary Tract Infections
• Fatigue
• Incontinence
• Erectile Dysfunction

AFTER CANCER
Solutions for Sexual Health
Cancer Treatment
RADIATION

SIDE EFFECTS OF PELVIC RADIATION

• Loss of Hair
• Changes to lining of vagina
• Narrowing
• Scarring
• Vaginismus
• Nerve Damage
• Blockage of blood supply to penis
• Lower Testosterone Levels

PROBLEM / SYMPTOM

• Altered Body Image
• Painful Intercourse
• Low Energy/Fatigue
• Mood swings
• Irritability
• Urinary Tract Infections
• Fatigue/Loss of Interest
• Incontinence
• Erectile Dysfunction

AFTER CANCER
Solutions for Sexual Health
Cancer Treatment
Hormone Therapy/Pain Medications

**SIDE EFFECTS**
- Decreased hormone levels
- Changes to lining of vagina
- Lower Testosterone Levels

**PROBLEM / PATIENT SYMPTOM**
- Decreased sexual desire/pleasure
  - Common symptom of depression
- Erectile dysfunction
- Urinary/bowel dysfunction
- Inability to orgasm

*AFTER CANCER*
Solutions for Sexual Health
CASE STUDY
Oophorectomy/Chemotherapy/Ovarian Cancer

Chief Complaint:
Low libido

History:
• 47 year old married female
• Ovarian cancer two years ago
• Hysterectomy, removal of ovaries
• Chemotherapy
• Since treatment has had pain with penetration and no interest in sex
• Oncologist gave her vaginal estrogen cream which didn’t help
THE WEB OF FEMALE SEXUAL PROBLEMS

SEXUAL DISORDERS
&PAIN/PENETRATION DISORDERS

unsatisfying encounter

Decreased desire

Decreased arousal

Decreased orgasm

inadequate stimulation

painless sex
Vulvo-Vaginal Atrophy

- FDA-approved
  - Minimally absorbed vaginal estrogen
    - Estradiol (Estrace Vaginal Cream®)
    - Conjugated equine estrogen (Premarin Vaginal Cream®)
    - Tablets (Vagifem®)
    - Ring (Estring®)
  - Oral ospemifene (Osphena®)

- Compounded
  - DHEA vaginal ovules (Vaginorm®)

NAMS position statement. Menopause 2013;20(9):888-902
Provoked Vulvodynia

- Diagnosis of exclusion; use topical estrogen cream if atrophic, cognitive behavioral therapy, urogynecologic physical therapy, dilators

- Complementary and alternative therapies

- Off-label Rx
  - Lidocaine gel (these formulations may be irritating when applied to the fourchette)

- Compounded Rx
  - Lidocaine (typically in a methylcellulose or other hypoallergenic base)
  - Gabapentin
  - Gabapentin + lidocaine
  - E2 + T in methylcellulose, sig: pea-sized amount to fourchette MWF, QS 3 mo, refill x3
    - E2 0.01% + 0.1% T
    - E2 0.1% + 0.3% T

Cotton Swab Test
The vestibule is tested at the 2-, 4-, 6-, 8-, and 10-o’clock positions. When pain is present, the patient is asked to quantify it as mild, moderate, or severe.

PAIN!
Dilators & Urogynecologic Physical Therapy for Vaginismus

- **www.vaginismus.com**
  - $44.95 set of 5 hollow plastic dilators
  - Handle can be cumbersome

- **www.middlesexmd.com**
  - $109 set of 7 solid white plastic dilators, easy to clean, smooth

- **www.soulsourceenterprises.com**
  - $19-$72 each, 9 sizes of colorful silicone dilators, warmer than plastic but not as smooth, flexibility may not be helpful for therapeutic dilation
  - $40-$55 each, 6 sizes of colorful rigid plastic dilators
  - Rigid polyurethane dilators for use after genital reassignment surgery also available

- **http://ergoerotics.com/130-waterproof-vibrating-slim-dilator.html**
  - $49 set of 4 vibrating hollow plastic dilators

- **http://www.coolwatercones.com/purchase.html**
  - $15 self-lubricating hydrocolloid cone that lasts for up to 4 weeks with refrigeration
  - For vaginal soothing after radiation therapy
BASSON’S
FEMALE SEXUAL RESPONSE CYCLE

- Emotional intimacy
- Motivates the sexually neutral woman
- To find/be responsive to
- Psychological and biologic factors govern arousability
- Sexual Stimuli

- Arousal and sexual desire
- +/- orgasm

Basson R. J Sex Marit Therapy, 2000; 26:51-65
## INTEREST / AROUSAL DISORDER

<table>
<thead>
<tr>
<th>PRE-MENOPAUSAL</th>
<th>POST-MENOPAUSAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive behavioral therapy</td>
<td>Cognitive behavioral therapy</td>
</tr>
<tr>
<td>Trial of discontinuing OCPs or DepoProvera®</td>
<td>If on HT, switch to transdermal</td>
</tr>
<tr>
<td>Bupropion (Wellbutrin®)</td>
<td>? Bupropion</td>
</tr>
<tr>
<td>?On demand buspirone (BuSpar®)</td>
<td>? On demand buspirone</td>
</tr>
<tr>
<td>?On demand buccal testosterone</td>
<td>? Sildenafil (Viagra®) for DM, neurologic problems, SSRI-induced problems</td>
</tr>
<tr>
<td>only with effective contraception or s/p hyst</td>
<td>Transdermal systemic testosterone</td>
</tr>
</tbody>
</table>


http://www.emotionalbrain.nl/

MULTIDISCIPLINARY TREATMENT OF FEMALE SEXUAL DYSFUNCTION

- Behavior modification
- Alternative medicine
- Sexual devices
- Structured sexual tasks
- Sexual pharmacology
- Treat systemic illnesses
- Consultations
- Evaluate medications
- Psychotherapy
- Pain management
- Patient and partner education

Krychman [www.medscape.org/viewarticle/575789_5]
Pre-operative discussion

- Any oncologic intervention in the pelvis can lead to both short-term and long-term post-treatment sexual and urological side effects.
  - Radiation – delayed
  - Surgery – immediate
- Pre-intervention discussion generally involves discussion of cancer treatment.
- Pre-intervention sexual/urologic sequelae are rarely discussed.

Typical Prostate Cancer Patient

58 M, diagnosed with prostate cancer after undergoing prostate biopsy for elevated PSA (6.5). Biopsy showed Gleason 3+4 Prostate cancer in 3 of 12 cores. Decision to undergo robotic assisted laparoscopic prostatectomy
58 M, diagnosed with prostate cancer after undergoing prostate biopsy for elevated PSA (6.5). Biopsy showed Gleason 3+4 Prostate cancer in 3 of 12 cores. Decision to undergo robotic assisted laparoscopic prostatectomy
# Prostate Cancer Risk

<table>
<thead>
<tr>
<th>Current Model</th>
<th>Extent of Disease Probability</th>
<th>Historical Model</th>
<th>Extent of Disease Probability</th>
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</thead>
<tbody>
<tr>
<td>Indolent Cancer</td>
<td>N/A</td>
<td>Indolent Cancer</td>
<td>N/A</td>
</tr>
<tr>
<td>Organ Confined Disease</td>
<td>74%</td>
<td>Organ Confined Disease</td>
<td>49%</td>
</tr>
<tr>
<td>Extracapsular Extension</td>
<td>17%</td>
<td>Extracapsular Extension</td>
<td>40%</td>
</tr>
<tr>
<td>Seminal Vesicle Invasion</td>
<td>4%</td>
<td>Seminal Vesicle Invasion</td>
<td>8%</td>
</tr>
<tr>
<td>Lymph Node Involvement</td>
<td>2.6%</td>
<td>Lymph Node Involvement</td>
<td>3%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Primary Treatment Outcome</th>
<th>5 Year</th>
<th>93%</th>
<th>5 Year</th>
<th>83%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Progression Free Probability after Radical Prostatectomy</td>
<td>10 Year</td>
<td>90%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Probability of Cancer-Specific Survival</td>
<td>15 Year</td>
<td>99%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Age: 58
PSA: 6.5
Gleason 3+4
3/12 cores positive

Memorial Sloan Kettering Treatment Nomogram: http://nomograms.mskcc.org/Prostate/PreTreatment.aspx
Erectile Dysfunction and Incontinence Risk?

Historical Rates:
  ◦ Continence = 95%
  ◦ Potency = 70%

Reality ➔

Eur J Surg Onc. 2014 Jul 18
Prostate Cancer Treatment

- All men undergoing radical retropubic prostatectomy will experience **SOME** post-operative erectile dysfunction and stress incontinence
- Recovery can take **YEARS**
- Many men are misinformed or misunderstand


**Misinformed Patients**

*Patient Preoperative Expectations of Urinary, Bowel, Hormonal and Sexual Functioning Do Not Match Actual Outcomes 1 Year After Radical Prostatectomy*

Daniela Wittmann,* Chang He, Michael Coelho, Brent Hollenbeck, James E. Montie and David P. Wood, Jr.†

From the Department of Urology (DW, CH, MC, BH, JEM, DPW) and Department of Social Work—Center for Sexual Health (DW), University of Michigan, Ann Arbor, Michigan

- 12% of patients expected BETTER urinary control
- 17% of patients expected IMPROVED erections

**Surgical Treatment**

Discussion of “sparing” or “not-sparing” nerves can often lead to increased expectations of post-operative recovery.

While “nerve-sparing” approaches increase chances of recovery, it should never be “expected”.
Post-Operative Rehabilitation

Post-op Rehabilitation should begin before surgery. Good to understand keys to recovering urinary control and erections post-operatively:
• Urinary control - Kegel Exercises
• Erections - Kegel Exercises, +/- PDE-5 (e.g. Viagra) and/or Vacuum erection devices
Post-Operative Regret

Regret is common (>20% of men)

Most influenced by post-operative erectile dysfunction and incontinence

More common in men undergoing robotic surgery
  ◦ Expectations are higher?
  ◦ Marketing?
Health Related Quality of Life – Post-Treatment

### Urinary Incontinence

<table>
<thead>
<tr>
<th>Treatment</th>
<th>EPIC Mean Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>HDXRT</td>
<td>86</td>
</tr>
<tr>
<td>I-125</td>
<td>86</td>
</tr>
<tr>
<td>RP</td>
<td>73</td>
</tr>
</tbody>
</table>

### Bowel Function

<table>
<thead>
<tr>
<th>Treatment</th>
<th>EPIC Mean Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>HDXRT</td>
<td>86</td>
</tr>
<tr>
<td>I-125</td>
<td>40</td>
</tr>
<tr>
<td>RP</td>
<td>93</td>
</tr>
</tbody>
</table>

### Sexual Function

<table>
<thead>
<tr>
<th>Treatment</th>
<th>EPIC Mean Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>HDXRT</td>
<td>28</td>
</tr>
<tr>
<td>I-125</td>
<td>38</td>
</tr>
<tr>
<td>RP</td>
<td>25</td>
</tr>
</tbody>
</table>
The effects of multidisciplinary rehabilitation: RePCa—a randomised study among primary prostate cancer patients

K B Dieperink1, C Johansen2, S Hansen1, L Wagner3, K K Andersen4, L R Minet5 and O Hansen1

Conclusion: Multidisciplinary rehabilitation in irradiated PCa patients improved urinary and hormonal symptoms, and SF-12 physical QoL.
What about the Partner?

Survivorship After Prostate Cancer Treatment: Spouses’ Quality of Life at 36 Months

Janet Harden, PhD, RN, Martin G. Sanda, MD, John Thomas Wei, MD, Hossein N. Yarandi, PhD, Larry Hembroff, PhD, Jill Hardy, BA, and Laurel Northouse, PhD, RN

Conclusions: Spouses continued to experience negative appraisal of caregiving, which affected QOL 36 months after their husbands’ treatment for prostate cancer. Additional studies related to factors that influence spouse QOL during survivorship will help guide clinical practice.

Knowledge Translation: Spouses who experienced more bother related to urinary, sexual, and hormonal function experience more stress and worse QOL at 36 months post-treatment. Spouse appraisal can have a significant effect on QOL. Offering counseling to couples following treatment for prostate cancer many improve QOL by helping couples manage relationship intimacy.
Conclusions

- Prostate Cancer treatment is very successful at managing prostate cancer with high cancer specific survival.

- With prolonged survival after CAP treatment, survivorship issues specific to CAP (e.g. ED and incontinence) become more important.

- Perioperative counseling focuses on the cancer.

- Rehabilitation can help, but ED and incontinence are COMMON and UNDERREPORTED/APPRECIATED.

- A team approach that begins pre-op is ideal.
## COMMUNICATION GAP

### PROVIDERS

- Economics of medicine/no time
- No formal training
- Assume patients will request help if they need it
- Assumptions (age, marital status, sexual orientation)
- Sexual issues are not medical issues
- Embarrassment for self and patient
- Privacy concern for patient
- Patient accompanied by family members/spouse
- Not the right time
- Don’t have answers

### PATIENTS

- Sexual issues are not medical issues
- Focused on physical treatment for the cancer
- Not normal or expected
- Don’t have the terminology
- Embarrassment for self and provider
- Fear of a negative reaction, being judged
- "Perfect Patient” syndrome
Distress Tool Screening: The Thermometer and the Problem List

First, please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.

Second, please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.

YES NO

- Child Care
- Housing
- Insurance/financial
- Transportation
- Work/school
- Appearance
- Bathing/dressing
- Clothing
- Changes in urination
- Constipation
- Diabetes
- Fatigue
- Feeling
- Feeding Swallow
- Fever
- Getting around
- Indigestion
- Memory/concentration
- Mouth sores
- Nausea
- Nose dry/congested
- Pain
- Sexual
- Skin dry itchy
- Sleep
- Tingling in hands/feet

Other problems

Emotional Problems
- Depression
- Fears
- Nervousness
- Sadness
- Worry
- Loss of interest in usual activities
- Spiritual/religious concerns

Family Problems
- Dealing with children
- Dealing with partner
- Dealing with close
- Financial

Physical Problems
- Dealing with illness
- Dealing with treatment
- Dealing with cancer
- Dealing with life changes
- Dealing with family issues

Distress 0

Distress 1

Distress 2

Distress 3

Distress 4

Distress 5

Distress 6

Distress 7

Distress 8

Distress 9

Distress 10

No Distress

AFTER CANCER
Solutions for Sexual Health
NCCN Guidelines for Survivorship
FEMALE

Please answer the following questions about your overall sexual function:

- Are you satisfied with your sexual function? Yes/No
- If no, please continue.
- How long have you been dissatisfied with your sexual function?

Mark which of the following problems you are having, and circle the one that is most bothersome:

- Little or no interest in sex
- Decreased genital sensation (feeling)
- Decreased vaginal lubrication (dryness)
- Problem reaching orgasm
- Pain during sex
- Other

Would you like to talk with your doctor or another team member? Yes/No
# NCCN Guidelines for Survivorship: MALE

## OVER THE PAST 6 MONTHS:

<table>
<thead>
<tr>
<th>Question</th>
<th>Very Low</th>
<th>Low</th>
<th>Moderate</th>
<th>High</th>
<th>Very High</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. How do you rate your confidence you could get and keep an erection?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2. When you had erections with sexual stimulation, how often were your erections hard enough for penetration (entering your partner)? No sexual activity</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. During sexual intercourse, how often were you able to maintain your erection after you had penetrated (entered) your partner? Did not attempt intercourse</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. During sexual intercourse, how difficult was it to maintain your erection to completion of intercourse? Did not attempt intercourse</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. When you attempted sexual intercourse, how often was it satisfactory for you? Did not attempt intercourse</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

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*NCCN Guidelines for Survivorship: MALE*

*AFTER CANCER*

*Solutions for Sexual Health*
Assessments / History

- How long has the problem been present?
- Is the problem related to time, place, or person?
- Do you feel comfortable with how your body looks?
- Is there a loss of sex drive or dislike of sexual contact?
- Are there problems in the relationship?
- What are the stress factors as seen by the patient and the partner?
- Is there other anxiety, guilt, or anger not expressed?
- Are there physical problems such as pain felt by either partner?
- Do you see yourself as sexually attractive?
- Do you wish to have these issues discussed only in private, or with your partner present?
- Is there inability to communicate about initiating, pacing, or shaping sexual activities?
Communicating Beyond Words
Bring Back That Loving Feeling

Starting Over and Sexual Scripts

- Learned behaviors, feelings, and meaning people ascribe to sexual behavior
- Set of thoughts and actions as it relates to sex that dictate the WHO, HOW, WHAT, WHERE, WHEN
- How people express love and intimacy
- After Cancer - the script will often need to change or physical expression of love/intimacy ceases
Points to Remember

- Common for patients to have sexual dysfunction during and after treatment and patients often suffer in silence.
- Healthcare providers need to normalize this topic for patients/determine the practice behaviors regarding distress tool screening/assessments.
- We should assume every patient potentially wants to be a sexual person.
- Sexual dysfunction can impact patients' lives in all ways, physically, emotionally, psychologically and spiritually.
- Sexual dysfunction can impact patient's relationships with a partner/spouse or potential relationship.
- Sexual Health issues should be treated as a medical issues.
- Screening for distress should be both in writing and in person.
- There are resources to help.

AFTER CANCER
Solutions for Sexual Health
Resources for Sexual Health (alphabetical)
April 2014, veronika-kolder@uiowa.edu

Anorgasmia
In addition to some of the books below, you may want to recommend the practical advice available at http://www.angelfire.com/dc/currentevents/vibfaq2.htm.

Bibliotherapy

Women

Teens