Sexuality, Intimacy, & the Ostomate
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Objectives
• Explain sexual dysfunction as a complication of pelvic surgery
• Describe treatment for female and male sexual dysfunction
• Explain different communication models

Definitions
• Sexuality
  ...a central aspect of being human throughout life encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors.” (WHO, 2006a)
Definitions

- Intimacy

Close familiarity or friendship; closeness; something of a personal or private nature

Sexuality & Intimacy

- Physical
  - Genital stimulation
    - Manual
    - Oral
    - Rubbing
    - Vibratory
    - Penetrative
  - And everything else!
    - Hand holding, cuddling
    - Stroking, massage
    - Kissing

Sexuality & Intimacy

- Emotional/Intimacy
  - Talking
  - Laughing
  - Spending time together
  - Flirting
  - Dating
Why is this important?

• Studied and reported in the cancer literature, but one of the least-addressed aspects of cancer care
• Less likely than other treatment-related SE to resolve over time
• Part of holistic care
• Limited scope in studies (e.g. fertility, contraception, menopause, erectile function, or capacity for intercourse) Hordern, A. 2008.

What do our patients tell us?

• They don’t know how to talk about it
• They are embarrassed to talk about it
• They want us to bring it up
• They wish they knew more about how their sexuality was going to be changed by their treatment
• They want to know if/when things will get back to “normal”

Success

“I met the man of my dreams in September of this year. I never thought I would be in a relationship after my ostomy surgery. I remember the day I finally told him about my ileostomy, I was so nervous! After I finally told him he looked at me and said “Is that what you were worried about. Is that all you were worried about telling me? Did you really think that would make me look at you any differently? You are amazing! Just because you have to wear a bag doesn’t make you less amazing, if anything it makes you even more so.” Last night he proposed to me and I accepted.”
Struggles

• “I am married and had an ostomy this year and still don’t know how to deal with this. My husband has hardly seen my bag. I am very self-conscious about it. I really want to be intimate but I feel so disgusted with this awful bag attached to me.”

• “I have had an ostomy for two years. I have dated a few times but when I tell the guy about my ostomy that’s the end of that. In the beginning they tell me how great I am or how compatible we are but when I tell them about my pouch then we are not compatible.”

What do we know?

• Reese et al 2014
  – N=141 (18 past ostomy, 25 current, 98 no)
    • Survey assessing sexual outcomes body image distress, and depressive symptoms
    • Past and current ostomy groups had worse medical impact on sexual function than those with no ostomy hx (p<0.001)
    • 74% of female respondents reported sexual dysfunction (100% current, 75% past, 64% never)
    • 65% of male respondents reported ED (67% current, 82% past, 60% no)
    • Sexual dysfunction common irrespective of gender and ostomy status

Sexual Response Cycle

• Desire
  – Having an interest in sexual activity

• Excitement
  – Arousal, feeling “turned on”
  – Faster heart beat, higher BP, heavy breathing, blood goes to genitals

• Orgasm
  – Sexual climax
  – Intense pleasure controlled by the nervous system

• Resolution
Sexual Dysfunction

A problem during any phase of the sexual response cycle that prevents the individual or couple from experiencing satisfaction from sexual activity.

Female Sexual Dysfunction

- Complex/multifactorial
  - Sexual desire disorder
  - Subjective sexual arousal disorder
  - Genital arousal disorder
  - Combined sexual arousal disorder
  - Persistent sexual arousal disorder
  - Orgasmic disorder
  - Vaginismus
  - Dyspareunia

El-Bahnasway et al. 2011
Female Sexual Dysfunction

- Anatomy
  - Internal
    - Vagina, fallopian tubes, uterus, ovaries
    - Nerves
  - External
    - Labia, clitoris, vestibular bulbs

Innervation of female pelvis

General Population

- Sexual desire
  - 31% lifetime
- Vaginal dryness
  - 23%
- Infrequent orgasms
  - 5-40%
- Inability to achieve orgasm
  - 16-25%
- Pain during or after intercourse
  - 3-48%
Male Sexual Dysfunction

• Erectile dysfunction
  — Maintain
  — Sustain
• Ejaculation disorders
  — Premature
  — Inhibited/delayed
  — Retrograde
• Low libido

Male Sexual Dysfunction

• Anatomy
  — Prostate
  — Seminal vesicles
  — Penis
  — Testes
Innervation of male pelvis

General Population

- Erectile Dysfunction
  - Massachusetts Male Aging Study
    - Increases with age
      - <40: 1-9%
      - 40-59: 2-9%
      - 60-69: 20-40%
      - >70: 50-75%

Incidence of Sexual Dysfunction

All ostomy patients are at risk of having sexual dysfunction of some kind that will interfere with their QoL. It may be small changes in feelings of sexuality or major changes in the body causing an inability to engage in sexual activity.
INSPIRE Quotes

• "If the together connection is missing for you, I would suggest getting some professional counseling as a couple. Some issues are just too big to get over on our own and there is nothing wrong with seeking professional help”

• “Your success with relationships will come from how YOU FEEL about your new body not how others feel. Life and love and people are about FAR MORE than what our bodies look like”

Incidence of Sexual Dysfunction

• Cystectomy
  – Male: Removal of bladder, prostate, seminal vesicles & transection of vas
    • ~100% ED without nerve sparing technique
  – Female: removal of bladder, uterus, ovaries, fallopian tubes & historically, anterior 1/3 of vagina; >50% incidence in sexual dysfunction reported
    – Diminished ability or inability to achieve orgasm: 45%
    – Decreased sexual desire: 37%
    – Dyspareunia: 22%
    – Cleveland Clinic data: only 48% of women able to have successful vaginal intercourse following cystectomy

• Hysterectomy
  – More than 600,000 performed annually
  – Disruption of nerves/anatomy
    • Main branches of plexus beneath uterine arteries
    • Vesical innervation
    • Dissection of paravaginal tissue
    • Removal of cervix
  – Leads to
    • Loss of libido
    • Dyspareunia
    • Vaginal dryness
    • Short vaginal vault
Incidence of Sexual Dysfunction

- Proctocolectomy
  - Erectile dysfunction: 3 – 13.5% incidence of ED
  - Age still a risk factor
  - Female sexual dysfunction: limited data
    - Some report an increase in sexual activity (Especially in inflammatory bowel population)

- Rectal cancer surgery
  - Women
    - Dyspareunia
      - Excision: 6%
      - APR: 60%
    - Alteration in orgasm
      - APR: 10%
  - Men
    - ED
      - Excision: 39%
    - Alteration in ejaculation
      - Excision 0-40%
  - APR a/w higher incidence of sexual dysfunction compared with sphincter preservation

Causes of FSD

- Cystectomy
  - Transection of NVB on lateral walls of vagina
    - lack of blood engorgement to clitoris and vagina
  - Denervation = loss of lubrication = sexual arousal disorder
  - Vaginal resection = narrowing, shortening = dyspareunia
  - Body image concerns = scars, ileal conduit

Donovan, Thompson, Hoffee. 2010
Gontero et al 2006
Causes of FSD

- Hysterectomy + oophorectomy
  - Loss of ovarian hormones
    - Decreased libido
    - Vaginal dryness
    - Hot flashes
    - Mood swings
    - Fatigue

Cause of FSD

- Proctocolectomy
  - Limited data
    - Vaginal stenosis, retroversion of the uterus = dyspareunia
    - Positional vaginal drainage
  - Some data report an increase in sexual function, esp in inflammatory bowel population

Causes of FSD

- Rectal Cancer Surgery
  - Damage to pelvic autonomic nerves
Causes of MSD

• Cystectomy
  – Removal of prostate
    • If NVB damaged = ED
    • Prostate-sparing not common due to concern for cancer recurrence
    • Anejaculation
  – Body image concerns
    • Scars
    • IC

• Rectal cancer surgery
  – Damage to pelvic autonomic nerves
  – Reports of ED vary
    • 15 – 92%
    • Sphincter saving: 14 -73%
Other Causes

- Age
  - Menopause/declining estrogen levels
  - Declining testosterone levels
- Tobacco use
  - Nicotine disrupts genital hemodynamics
  - Facilitates a cascade of vascular & chemical events
  
- Chronic illness
  - HTN, DM, HLD, depression, anxiety

Other Causes

- Neoadjuvant, adjuvant, salvage treatments
  - Chemotherapy
    - Nausea, vomiting, anorexia, fatigue, neuropathy, alopecia
    - Menopausal symptoms
    - ED
  - External Beam Radiation
    - Fatigue, decreased interest
    - Vaginal dryness/shortening = dyspareunia
Not Just Physical

• Psychological, emotional aspects
  – Poor self image
  – Distorted self image
  – Changes in appearance
  – Concerns about attractiveness
  – Feeling “less of a man/woman”
  – Reproductive capacity
  – Social isolation
  – Anxiety
  – Depression
  – Sadness

INSPIRE Quotes

“Your feelings of anger are justified and warranted as having an ostomy is a life changing event. Don’t let it stop you from living your life and choosing happiness. It is a process to accept and deal with it on a daily basis, but it does not define who you are…”

Positives

• Ostomy surgery may have a positive effect on sexuality
  – Relief of painful conditions like Crohn’s or UC
  – Pouch containment of incontinence rather than absorbent products
  – Management of a fistula or obstruction
Evaluating Sexual Dysfunction

Clinician-Administered Sexual Function Assessment

- Female Sexual Function Index (19 items)
- Golombok-Rust Inventory of Sexual Satisfaction for Men & Women (28 items)
- International Index of Erectile Function (15 items)
- Sexual Health Inventory for Men (6 items)

Treatment of FSD

- Vaginal dryness
  - Water soluble lubricants
    - Replens, Lubric
    - Astroglide, KY Jelly
- Vaginal shortening
  - Vaginal dilators
- Dyspareunia
  - Vaginal dilators
  - Anesthetic gels
  - Changing positions
    - Decreases penetration
Treatment of FSD

• Body image disturbances
  — Ileal conduit
  — Empty the urine
  — Check for proper fit
  — Pouch covers/belly bands

• Side effect management
  — Fatigue
  — Nausea
  — Pain

Treatment of FSD

• Vaginal dilators
  — Gradually expand the vagina
  — Use 2-3 times/week for 10-15 minutes
  — Best if this is done for at least 3 years unless a person is sexually active
INSPIRE Quotes

“My cancer was rectal. When I had radiation it was aimed at the rectal area which also affected the vaginal area. During the six weeks I got burned so badly that I had to go without radiation for one week. After it was done, I was given, I guess you would call it a dildo, to help stretch the area back to normal. Well it didn’t work! I can’t let my husband penetrate me without pain. It’s been four years now. We do have sex though. At least we both get satisfied. We do oral sex & it works well for us.”

Treatment of MSD

• Erectile Dysfunction
  – Vacuum Erection Device (VED)
    • Cylinder, pump, elastic band
    • Improves O2 delivery & length
    • Pros: drug-free, no systemic SE, does not require stimulation, rehab and sexual activity, portable
    • Cons: Cumbersome, painful, decreases spontaneity, not covered by all insurance
Treatment of MSD

• Erectile Dysfunction (cont)
  – PDE5 Inhibitors
    • Prevent breakdown of cGMP by PDE-5 in the smooth muscle cells lining the vessels supplying corpus cavernosum
    • Require nerves to work properly (i.e. rely on the nerves to activate the chemicals within the penis that will lead to increased blood flow)
    • Sildenafil, vardenafil, tadalafil, avanafil
    • Pros: Simple, discrete, can se with VED
    • Cons: Efficacy, $$$, SE

PDE5 I

Sildenafil (Viagra): April 1998
Vardenafil (Levitra): August 2003
Tadalafil (Cialis): Nov 2003

Newer

Vardenafil (Staxyn): June 2010
Avanafil (Stendra): April 2012

Treatment of MSD

• Erectile Dysfunction (cont)
  – Intraurethral MUSE (alprostadil)
    • Increases intracellular cAMP
    • Pros: Quick onset, can use with PDE 5 I, easy
    • Cons: SE, several contraindications, $$$$
  – Intracavernosal injections (ICI)
    • Direct injection of medication into corpora cavernosa
    • Alprostadil, papaverine, phentolamine
    • Pros: Highly effective, quick onset, involve partner, cost effective
    • Cons: Needle!
Treatment of MSD

• Erectile Dysfunction (cont)
  – Implanted Penile Prosthesis (IPP)
    • 2 inflatable rods into corpora cavernosa connected to a pump reservoir. Pumps saline from reservoir into rods
      – Pros: Effective, increased spontaneity, high patient satisfaction
      – Cons: Surgery, costly, malfunction
Pros & Cons

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<thead>
<tr>
<th>Treatment</th>
<th>Pros</th>
<th>Cons</th>
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<tbody>
<tr>
<td>PD PDE-5I</td>
<td>Easy to take</td>
<td>Poor efficacy after surgery</td>
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<tr>
<td>VED</td>
<td>Noninvasive</td>
<td>Side effects</td>
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<tr>
<td>MUSE</td>
<td>Easy to use</td>
<td>Pain</td>
</tr>
<tr>
<td>ICI</td>
<td>High efficacy</td>
<td>High cost</td>
</tr>
<tr>
<td>Implant</td>
<td>High satisfaction</td>
<td>Surgical procedure</td>
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Treatment of MSD

- Penile shrinkage
  - Reported after prostatectomy due to unchallenged muscle tone
  - If muscles that surround the blood vessels are not contracting/relaxing with nocturnal erections → decr mass → shrink
- Treatment
  - VED
  - Stretching, fills penis with blood
Treatment of MSD

- Body image disturbances
  - Ileal conduit
    - Empty the urine
    - Check for proper fit
    - Pouch covers/ belly band
- Side effect management
  - Fatigue
  - Nausea
  - Pain

INSPIRE Quotes

“At age 30, I had surgery to remove a large rectal tumor and as a result have had a permanent colostomy for 26 years. The surgery and radiation treatment also caused permanent ED. My wife and I had enjoyed a close, intimate relationship before the surgery, but found many challenges reconnecting after. Fortunately, she never made me feel that I was less desirable because I had a pouch, but the ED was an issue for me. I didn’t feel like I could perform and this increased my anxiety and reduced my desire for intimacy. I decided to have a penile implant a year after the cancer surgery and that provided a much needed boost to my libido. We have enjoyed 25 years of intimacy since then and even after the implant failed about 10 years ago, we have enjoyed discovering together new ways to please one another. I’ve made it sound simple, but it was not. There were lots of tears, anger (mostly from me), embarrassing and challenging moments, but we always worked through them together.”

Hormone replacement

- Consider, if not contraindicated by underlying disease
  - Women
    - Vaginal estrogen cream
  - Men
    - Testosterone in bladder cancer/rectal cancer if no contraindications and pt has low T
    - Controversial in prostate cancer
Prevention?

• Female
  – Uterine/urethral sparing cystectomy
  – Vaginal sparing cystectomy
  – Different cuff closure
    • Tubular closure rather than A-P flap closure
  – Nerve sparing APR

• Male
  – Nerve sparing
    • Cystectomy, Prostatectomy, APR
  – Prostate sparing cystectomy

INSPIRE Quotes

“The debate about when to tell someone new is ongoing but my personal opinion is this: Don’t tell them after just the first couple of dates, and don’t wait until you’re just about to be intimate. Timing is important. I’ve had to learn how to read people over the years, and discern whether I think they are the type of person who would be accepting”

Undergarments

www.ostomysecrets.com

www.options-ostomy.com
Communication: Concepts

- Accommodation
- Adaptation
- Family/caregiver communication
- Health literacy
- Goals
- Non-verbal components of messages
- Relational tension

Wittenberg-Lyles, E., Goldsmith, J., & Ferrell, B. 2013

Communication: Barriers

- Lack of_____ (time, privacy, information)
- Knowledge/training
- Avoidance of sexual assessment & interventions
- Fear of embarrassing self
- Fear of offending patient
- Institutional issues
- Bias (ageism, sexual orientation)
Communication: Models

• SPIKES
  – Getting the Setting right
  – Patient Perception
  – Invitation
  – Giving Knowledge
  – Addressing Emotions
  – Summary/Strategy

Baer & Weinstein 2013

Communication: Models

• BETTER
  – Bring up the topic
  – Explain you are concerned with QoL, including sexuality
  – Tell patients you will find appropriate resources to address their concerns
  – Timing many not seem appropriate now, but they can ask for info or help at any time
  – Educate patients about the side effects of their cancer treatment
  – Record your assessment and intervention in the patient chart

Communication: Models

• 5 As
  – Ask
  – Assess
  – Advise
  – Assist
  – Arrange

Bober & Vierela 2012
### Communication: Models

**ALARM**
- Activity
- Libido/desire
- Arousal/orgasm
- Resolution
- Medical history

*Rusk and Golombock 1986*

### Communication: Models

**PLISSIT**
- Permission to ask about sexual concerns
  - Normalizes the experience
- Providing Limited Information
  - Clarifying concerns and misconceptions
- Providing Specific Suggestions
  - Based on patient concerns
- Intensive Therapy

### Communication

- Between patients and providers
- Between patients and partners
  - Encourage open discussion
    - Fears
    - Changing the routine
    - Adapting to new normal
Patient Advocacy/Resources

- Stoma City- Colontown
- INSPIRE
- The Stolen Colon
- Girls with Guts
- Meet an ostomate
- BCAN
- United Ostomy Association of America

Provider Resources

- United Ostomy Association of America
- American Cancer Society
- Crohn's and Colitis Foundation
- WOCN Society
- American College of Surgeons

Recommendations

- Averyt & Nishimoto 2014
  - Screening and assessment of sexual functioning should be included early in treatment for all pts [w/CRC] and continue during all stages of care
  - Pts may be reluctant to raise the topic-initiating conversations as part of standard of care can help facilitate discussions
  - Maintain referral resources and info re: treatment options for pts and their partners
Conclusion

• This is an important issue for ostomates and their partners
• Sexuality is complex and multifactorial
• Treatment options exist
• Upfront and continuing education is key
• Collaboration among health care professionals
• You don’t have to be an expert in everything—know your resources

Resources