

Intimacy, Sex and Bone Marrow Failure Disease

AA&MDSIF Patient & Family Conference

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July 12, 2009

Disclaimer

Sexuality, and the effects of medical conditions on sexuality, are highly individualized. Anything said later in this talk may or may not relate directly to you or your situation. Please feel free to include any personal history that you are comfortable sharing. Open, frank, friendly discussion is encouraged.

Overview

- Physiological impact on sexual function
- Emotional impact
- Healthy sexual function vs. sexual dysfunction
- Strategies to manage sexual dysfunction

The background...

- Sexuality and the “traditional” life cycle **
There are many variations to this...
 - Puberty
 - Courting
 - Career & Family building
 - Retirement
- Stressors – emotional and medical – can impact sexual function

Intimacy

- Feeling of being close or belonging together
 - Dialogue, transparency, vulnerability and reciprocity
- Sexual intimacy
 - Can include sexual intercourse, but these terms are not synonyms
 - Holding hands, kissing, massage, etc.

Sexual Function

- “Libido”
 - Drive / Motive / Wish
- Physical Sexual Functioning
 - Arousal / Plateau / Orgasm / Resolution

“Libido”

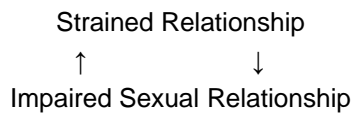
- “I’ve got no libido” can mean different things to different people.
- Literally: emotional sex drive.
- Three types of libido
 - Drive: Biological (Hormonal) Sex Drive
 - Motive: Emotional/Intimacy Mediated Drive
 - Wish: Sociological/Learned Expectations

Drive

- Many medical conditions, or their treatments, can affect drive
- Fatigue
- Hormonal

Motive

- Relationship is important
- Relationships often strained by serious medical conditions (and/or their treatments)



Wish

- Not "I wish I was having more sex"
- Expectation that one should be having sex or not having sex based on family, relationship, cultural and religious beliefs
- How sexual desire is expressed

Masters and Johnson sexual response cycle

- 4 distinct stages
- Very similar physiologic events for both men and women

Excitement Stage

- Males
 - Increase in blood flow to the penile blood vessels and tissue → erection
 - Testicles pulled closer to the body and tensing of scrotal skin
- Females
 - Vaginal lubrication, breast swelling, clitoral erection, labial size/shape changes
- Both
 - Increased heart rate, breathing rate and blood pressure along with muscle tension

Plateau, Orgasm & Resolution

- Plateau
 - Further increases in heart rate, sexual pleasure, muscle tension
- Orgasm
 - Conclusion of plateau phase
 - accompanied by quick cycles of muscle contraction in the lower pelvic muscles
 - In men, usually associated with ejaculation
- Resolution
 - occurs after orgasm
 - allows the muscles to relax, blood pressure to drop and the body to slow down from its excited state

Impact of medical illness on sexuality

- Pathophysiology of disease
- Effects of surgery
- Medication effects
- Radiation
- Emotional reaction to illness
- Partner's emotional reaction to illness

Pathophysiology of bone marrow failure illnesses

- Anemia
 - Chronic fatigue, shortness of breath
 - Sometimes chest pain
- Neutropenia
 - Increased risk for infection
- Thrombocytopenia
 - Easy bruising & bleeding

Medication Effects

- ATG & ALG
 - Fatigue and hypertension
- Neupogen (filgrastim)
 - Nausea/vomiting, muscle aches, fatigue, flu-like symptoms
- Leukine
 - Bone pain, fatigue, nausea, flu-like symptoms
- Lenalidomide (Revlimid)
 - Fatigue, nausea, joint pain,

Medication Effects - Continued

- Cellcept (mycophenolate mofetil)
 - Fatigue, dizziness, weakness, vomiting, joint/back/muscle pain
- Vidaza (azacitidine)
 - Nausea/vomiting, diarrhea, fatigue, fever
- Erythropoietin
 - Joint pain, headache

Emotional reaction to illness

- Many challenges to medical illness
 - Life-style
 - Independence
 - Activities may change
- Sadness, fear and anxiety can result
- Impact on sexual function

Partner's reaction to illness

- Their feelings about the illness → can lead to avoidance of intimacy
- Avoiding intimacy to reduce the spouse's anxiety
- Using the illness to avoid intimacy for reasons not related to the illness

Factors that impair return of sexual function

- Increasing age
- Poor quality of sexual & non-sexual relationship before onset of illness
- Medical severity
- Inability to accept diagnosis
- Alcoholism & substance abuse

Improving Sexual Problems

- Talk with your partner (almost always the 1st step)
- Self-help
 - Accurate information
- Professional help
 - Primary care doctor
 - Hematologist/oncologist
 - Mental health – Psychiatrists, Psychologists, Master's level Social Worker

Talking about sex with your partner

- Pick a good time
- Start slow – 1-2 goals
- Focus on positives
- Avoid arguments
- Be open about your fears → sexual rejection, breaking up, survival & recurrence
- Be a good listener

Sexual Dysfunction

- Decreased libido
- Pain during intercourse
- Erectile dysfunction
- Menopausal symptoms
- Anorgasmia

Decreased Libido

- Treat underlying causes
 - Depression
 - Hormonal = very low testosterone
- Increase libido by:
 - Exercise
 - Making time
 - Using other senses
 - Do things that make you feel attractive

Pain during intercourse

- Commonly chronic pain
- Ways to manage:
 - Plan sex during time of day when pain level is lowest
 - Warm bath or shower to ease stiffness – muscle relaxation techniques
 - Time with pain medications

Erectile dysfunction

- Many causes:
 - Anxiety and depression
 - Low testosterone
 - Medications
 - Antidepressants, anti-anxiety meds
 - Nerve damage
 - Sometimes caused by chemotherapy

Restoring erections

- PDE inhibitors
- Vacuum constriction devices
- Penile injections
- Intra-urethral suppositories
- Penile prosthesis

Menopausal symptoms

- Hot flashes
- Vaginal dryness
- Treatment options:
 - Vaginal lubricants
 - Replacement hormones (estrogen and testosterone)
 - Topical estrogen

No orgasms

- Rare to develop a new problem as a result from illness or treatment
 - One exception → certain SSRI antidepressants
- Reaching orgasm easier
 - Focus on desire and arousal instead of orgasm itself
 - Change goals if the focus of orgasm results in too much stress
 - Try self-stimulation

Fertility

- Can be decreased due to treatments
 - Discuss with your doctors
 - Sperm and ovary banking
- Need to be careful with some meds that can cause birth defects

Suggested Reading

- Leslie Schover, PhD. "Sexuality and Fertility After Cancer"
- Stephen Levine, MD. "Sexual Life: A Clinicians Guide"
