Intimacy, Sexuality and Bone Marrow Failure Disease

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Objectives

- Define Sexuality and Intimacy
- Dispel myths
- Look at the impact of bone marrow failure disease on sexuality and intimacy
- Discuss options to help manage difficulties with sexuality and intimacy

What is Sexuality?

What is Intimacy?
Sexuality and Intimacy are not life or death issues but are very real quality of life issues

Prevalence of Sexual Dysfunction

- Sexuality can signify:
  - “I am alive”
  - “I am human”
  - Acceptance and validation by partner
- Resuming intimate relationships (whether sexual or not) is one way of feeling that life has resumed to ‘normal’ again
- 40 – 100% of patients will experience some form of sexual dysfunction after cancer treatments (assumptions from cancer literature)

Myths

- If we can’t have intercourse, it isn’t worth it to get aroused
- “This should be the last thing on my mind”
- “It doesn’t matter, I am single”
- All physical contact must lead to sex
- Men enjoy sex more than women
- Sex is a failure if both partners don’t reach orgasm
Myths

- No one will want me if they know I have a chronic illness
- My partner isn’t interested in me anymore
- “I will never feel sexy again”

How does bone marrow failure disease impact intimacy and sex drive?

Physically, Psychologically and Socially

Treatment Side Effects

Emotional Side Effects

Side Effects of Treatment

- Chemotherapy:
  - “Chemo Brain”
  - Hormone changes: Hormone levels can be disrupted, Menopausal symptoms, Hot flashes, Libido change
  - Hair Loss
  - Nausea
  - Vaginal Dryness & changes in the vagina’s integrity
  - Peripheral neuropathy
  - Mucositis / Mouth problems
  - Infertility possible
  - Pain
  - Cardiac and Respiratory problems
  - Gleevec & Thalidomide – pose threat to fertility
Stem Cell Transplant

- Present a higher risk of infertility
- Recent study published in Sept 2007, American Society of Hematology, found that men tend to have higher rates of sexual interest recovery than females, however, 40% men and 85% of women reported problems that disrupted sexual function after 5 years
- Should improve in 1 to 2 years but testosterone levels checked and other enhancement aids may need to be used
- Vaginal depth can be affected, causing painful intercourse (beyond just being put into a medical menopause). Vaginal GVR can cause painful intercourse as well.
- Challenging to reconnect after the Fear of getting sick or being infected or Withdrawal - both emotional and physical
- Fatigue

Impact of Side Effects on Sexuality & Intimacy

- Many of the SSRI’s and other psychotropic medications we prescribe to help with mood can further interfere with desire and sexual response. Speak to your health care team about options for a different medication or medications that may be used in addition to help improve sexual response
- Loss of Libido (emotional and physical)
- Skin irritation or pain that can alter previous sexual desires or routines
- Fatigue
- Loss: Fertility, feelings of sensuality, role changes
- Negative self perception (hair loss, scars, role change, etc)
- Social Life

Impact of Side Effects on Sexuality & Intimacy

- Other quality of life issues
  - Anxiety, depression, nutrition
  - Smoking and alcohol use can also affect erection difficulties and lack of interest
Now What?

Questions and Answers to Common Concerns

The Parts of Sex Affected by Treatments and Options

Drugs Associated with Sexual and Reproductive Dysfunction

- Antiemetics, Sedatives and Tranquilizers
  - Sedation
  - Decreased libido
- Antidepressents (Prozac, Paxil, Zoloft)
  - Delayed orgasm
  - Impotence
- Narcotics (Morphine, Dilaudid, Codeine)
  - Decreased libido
  - Sedation
  - Impaired potency

Specific Suggestions:

- Women – biggest complaints are vaginal dryness and libido response
  - Water-based Artificial lubrication: Astroglide, Gyn-Moistrin, KYlubriicant, Replens, Vitamin E oil, yogurt
  - Internal vaginal dryness – internal lubricants such as Replens, yogurt
  - Heighteners that help with clitoral sensitivity and excitement (websites like pureromance.com has several options and are safe places to shop)
  - Vibrators
  - Dilators – to help with decreasing anxiety or help with vaginal training if having a hard time with climaxing, can also help with decreasing vaginal pain, along with practicing kegel exercises
  - Estradiol-releasing vaginal ring (Estring), Testosterone Patch, Vagifem, Premarin or Estrogen Creams
  - Eros-C®
- Are Testosterone patches an option to help with libido response?
Specific Suggestions:

- **Women – biggest complaints are vaginal dryness and libidic response**
- **Vaginal Pain:**
  - It is possible that the vaginal canal has shrunk and dilator therapy may be appropriate, can use a dildo or vibrator as well
  - Consult with your gynecologist or a PT who specializes in pelvic floor exercises

Vaginal Dilators

- Get your MD write a prescription to encourage the normalcy and decrease shame and/or embarrassment
- Use during and after treatment, especially if you are not sexually active
- Assists in learning to relax vaginal muscles
- Even if you're not sexually active, it is important to maintain patency for exam comfort
- Scar tissue may form from GVHD, important to help minimize the long term effects
- Efficacy is maximized when used early. Recommended use is 3x/week

Libido and Response

- Hormone levels may need to be tested
- Practice Kegel exercises to help with better control and response
- Be aware of how the time of day impacts your libido - may need to get creative
- May need to get creative with positioning to help with enhancing response or control
Libido and Response

- Use of enhancement medications and/or devices may be helpful (Eros-C, Muse/Caverject, Penile pumps, etc.)
- May require redefining your expectations (as well as your partner). You can still have very pleasurable sexual experience without an erection. Focus on touch, sensation, pleasurable feelings, the use of assistive devices for both partners.
  - May need to use other forms of sexual stimulation, such as mutual masturbation, reading fantasy and erotica to one another, redefining sexual intimacy to include being naked and cuddling, massage or other touch techniques.

Orgasm

- Changing expectation from a “body thing” to a “mind thing”
- Sensate focus exercises, American Cancer Society’s booklet Sexuality and Cancer: For the Woman Who Has Cancer & Her Partner and Sexuality and Cancer: For the Man Who Has Cancer & His Partner
- Re-explore pleasurable body experiences alone
- Kegel exercises

Orgasm

- “Teasing” exercise – start early in the day, leave love notes, or openly discuss your intimate plans with your partner. Increase foreplay, don’t rush. Start with gentle touch first thing in the morning and leave each other wanting to continue when you return home.
- Can use enhancement aids and devices such as penile pumps, vibrators, heightening creams/oils, etc.
"I don’t feel attractive"
- Include good nutrition and exercise to help how you feel about yourself
- Look good feel better class or see a beautician or cosmetologist who can help you with the changes in your skin/hair
- Make an appt with a social worker or counselor
- Be patient with the physical effects, as you get well you will feel well and look better
- Your diagnosis may have changed how you look, but it does not have to change how you feel about yourself

Body Image Exercises
- Identify negative thoughts and try to replace with positive thoughts and affirmations
- Practice Positive Affirmations
  - "I accept my body I will do everything I can to love and help it heal"
  - My body supports my healing process
- Focus on the things that haven’t changed (find three things you like about yourself)
- Meditation and Relaxation
- Celebrate the person you are and the body you have

Fatigue
- Plan for time of day energy is greatest and when most refreshed
- While adjusting back to life – use assistive devices that can help conserve your energy
- Accept and ask for help so you can do what you want to do
- Take pain medication 1/2 - 1 hour prior to activity, including intercourse
- Practice deep breathing or relaxation techniques
- If sex is important go slow and be creative
- Exercise combats fatigue and helps relax and warm muscles
- Assess for depression
Fear of Rejection

- **When do I Disclose?**
  - Role play with a friend
  - Discuss story in multiple settings
  - You should educate yourself on implications of treatment on sexuality & fertility
  - Identify intimate relationships in which you would feel comfortable asking questions, sharing their story, showing their scars, etc.

- **What if my partner isn't interested?**
  - Self pleasure
  - Remember most of the time it isn't about you
  - Couples counseling / Sex Therapist
  - Communicate about your needs, maybe there is underlying fear or anxiety on their part (see suggestions from NCI)

- **What if I am currently not partner?**
  - Self pleasure
  - Surround yourself around people who “fill you up”

Maintaining intimacy

- **Choose wisely:**
  - Get rid of any toxic relationships. These are not helpful to your physical or emotional health.
  - Surround yourself with individuals who you are able to be honest with and who provide you the support you need

- **Ask,** if your needs are not being met
  - (i.e.) “It’s not helpful when you say to me ‘everything is going to be okay’ or ‘everything happens for a reason’, what I need is for you to listen or to tell me this frustrates you too”

Maintaining Intimacy

- **Start with self pleasuring exercises to get to know your body again and what makes you feel good**
- Provide yourself with daily affirmations
- Chose one friend who you will meet with once a week
- Go to a day spa or spend a day pampering yourself (playing golf, going for a run, pedicure...) and reconnect with yourself
**Staying Connected to Family and Friends**

- Honesty and Communication
- Allow friends to help, assign them tasks
- Educate them on the “new normal”
- Schedule time with friends and family on your “on” time
- Change social setting to be conducive with your needs
- Avoid “toxic” relationships

**Tips: Talking to Your Partner About Your Sexual Needs, National Cancer Institute, 2002**

How do you talk to your partner about sex or intimacy after cancer treatment? Here are some ideas that have helped others: (this technique can also work with friends)

- Tell your partner how you feel about your intimate life and what you would like to change. You might tell him or her:
  - What is happening with your sex life
  - Your thoughts and beliefs about why your sex life is the way it is
  - How it makes you feel—e.g., scared, lonely, sad, or angry
  - What would please you or make you feel better

This approach avoids blame, stays positive, and gives your significant other a better sense about how you are feeling.

Here is an example of how you can talk to your partner:

- “We have made love only a few times since my diagnosis/treatment (fact).
- I think it may be because you aren’t attracted to me anymore (your belief).
- When we do not have sex, I feel very lonely, and I miss being close to you. Sometimes I also feel angry that this disease affects our sex life, too (your feelings).
- I would feel much better if we had sex more often—and if it was your idea more often (your needs).”
Tips: Talking to Your Partner About Your Sexual Needs, National Cancer Institute, 2002

- Listen to your partner's point of view:
  - Repeat what he or she says in your own words to show you understand.
  - Ask questions to show interest and caring.
  - Show support. Say things like, "You seem worried," or "I'm sure this is very hard for you."
  - Listen. Focus on your partner's comments, not on what you plan to say in response.

For the Couple

- Changing Sex Positions
  - Experimenting with different positions may decrease anxiety & go slowly at first
  - Allow yourself to get creative...create your "new normal!"
  - Find other ways to be sexual; sometimes being naked together is the most intimate experience
  - Get back to the basics
  - Communicate, communicate, communicate...we don't read minds!
  - Remember that problems before cancer don't magically disappear during/after cancer
  - See a therapist to help work through road blocks

Intimacy for the Couple with Children

- Partnership's don't work if you don't take time out for each other
  - Schedule a night out for the kids on a regular basis
  - Be honest with children, they have lots of questions
  - Express yourselves in front of your children
  - Find ways to connect with each child if you find that your activity level is limited
  - Laugh with them
Things to Remember

- Appropriate timing of activity may increase enjoyment of sex
- Get creative
- You have control over who you surround yourself with
- Communicate about your needs
- Find other ways to feel more sensual/sexual
- Rest during sex; it’s not a marathon
- Sex is not the only form of intimacy
- Patience and a sense of humor is a must
- **Skin is the largest sex organ and the brain is the most important sex organ – the possibilities are limitless!**

"...Intimacy need not end with [bone marrow failure disease]. You may need to redefine your ways of expressing intimacy, and you may need to experiment because what worked before may no longer work after" – Mayo Clinic Staff, 2003

Resources

- [www.pureromance.com](http://www.pureromance.com): sexual health resources
- [www.fertilehope.org](http://www.fertilehope.org): fertility information
- [www.AMDS.org/Learn](http://www.AMDS.org/Learn): Aplastic Anemia & MDS Informational Education's Online Learning Center
- [www.cancer.org](http://www.cancer.org): ACS, sexuality, fertility, managing side effects
- [www.gayhealth.com](http://www.gayhealth.com): LGBT resources
- [www.cancersupportivecare.com/sexuality.html](http://www.cancersupportivecare.com/sexuality.html): Cancer supportive care information
- [www.cancerpage.com/cancernews/cancernews1500.htm](http://www.cancerpage.com/cancernews/cancernews1500.htm): Cancerpage.com
- Leukemia Lymphoma Society, Fast Facts Sheet on Sexuality & Intimacy