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ASKING MAKES A DIFFERENCE: INTIMACY AND SEXUAL HEALTH AFTER CANCER

Ordinary understanding is seeing with the eye and hearing with the ear. Intimacy is seeing with the ear and hearing with the eye.



- Daido Roshi (Zen Mountain Monastery: Library of Dharma Discourses by John Daido Loori)

Objectives

- To have an increased awareness of:
 - the importance of intimacy and sexual health discussions for cancer survivors
 - practice standards and research around sexual health communication
 - the lived experiences among a variety of patients
 - easily accessible resources for use in your practice setting



What is sexual health?

Sexual health is a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity.

- World Health Organization, 2006



Two Truths and a Lie: Intimacy and Sexual Health After Cancer

- Intimacy and sexual health concerns are common in cancer survivorship.
- Asking about sexual health makes a difference in quality of life for cancer survivors.
- Screening for sexual health issues takes extra time and special training.



The first truth

Sexual health concerns are common
in cancer survivorship

Sexual health concerns are common

- Unlike many other physiological side effects of cancer treatment, sexual problems do not tend to resolve within the first year or two of disease-free survival; rather, they remain constant and fairly severe or even continue to increase.
 - Ganz et al, 1996
- Five years after diagnosis the majority of cancer survivors reported sexual health deterioration.
 - Seguin et al, 2020
- Sexual toxicity is “exceedingly common,” with 87% of respondents stating that cancer treatment had negatively impacted their sexual health.
 - Taylor et al, 2020

Different boat, same ocean...

- 57% of ovarian cancer survivors report negative effect on sexual functioning 2 years post-treatment
 - Correlation with poor quality of life, depression, anxiety, self-esteem, body image, relationship and partner issues
 - Desire: to have discussions with their care providers, and that the *provider* was the one to initiate the conversation
 - Fischer et al, 2019
- “There was absolutely no discussion about how treatment would impact my sex life. ... I’m more than my sexuality, but it’s a big part of me, and to think about losing it even temporarily is not cool.”
 - Frankly: Conversations about sex throughout the cancer journey - Liz, age 47. Cancer-Network.org
- > 90% of Adolescent and young adult cancer survivors considered sexual health information from care providers to be important
 - 41% received information; 21% satisfied with interaction
 - Albers et al, 2020
- Treatment associated sexual dysfunction has a clear psychological impact on gay men. For those experiencing ED, or diminished libido, this could result in a self-imposed exclusion or disqualification from sexual engagement, leading to feelings of isolation and psychosocial distress.
 - McConkey & Holborn, 2018



ASCO Guidelines

- It is recommended that there be a discussion with the patient, initiated by a member of the health-care team, regarding sexual health and dysfunction resulting from cancer or its treatment.
- Psychosocial and/or psychosexual counseling should be offered to all patients with cancer, aiming to improve sexual response, body image, intimacy and relationship issues, and overall sexual functioning and satisfaction.



- <http://ascopubs.org/doi/full/10.1200/JCO.2017.75.8995>

The second truth

Asking about sexual health makes a
difference in quality of life for cancer
survivors

When we talk about healing, we're not talking about the condition of your body as much as we're referring to the condition of your life.

- Bernie Siegel, MD & Yosaif August (Help Me to Heal, 2007)



Recently heard patient stories...



Bias affects the tone of our interactions and willingness to engage

Consider your bias with sexuality discussions:

age; gender; sexual orientation; relationship status; race; culture; language; religion;
physical ability; illness severity; life expectancy; parent in the room; and more



Asking makes a difference



- Single doesn't mean not sexually active
- Partnered doesn't mean one partner
- Gender of partner(s) doesn't dictate
 - Specific sexual practices
 - Need for contraception and fertility discussions
- Age, relationship status, physical barriers, mental health, housing situations...
 - *People are having more (or less) sex than we think!*

Adolescent & Young Adult Cancer Patients (AYACP) need for trustworthy information

- Barriers to discussions:
 - AYA: Feelings of shame
 - HCP: Presence of a 3rd party
 - Both: Limited information and educational materials
- AYA's want information
 - Prior to treatment (64%)
 - Web-based (66%)
 - From their healthcare provider directly (64%)
 - Albers et al, 2020
- What's most important to QoL?
 - Support from others.
 - Kaal et al, 2021
- Online information needs
 - AYAs expect HCPs to guide them to eHealth resources
 - van de Graaf et al, 2022
- Connectedness Requirements:
 - Authenticity; willing to foster a relationship; attentive to needs; humor; conveying respect, support, caring
 - Phillips & Haase, 2018

LGBTQ+ with feelings of invisibility

- “I think we might be able to discuss more openly how sex and sensuality can be an important part of coping/healing/recovery processes. I thought this aspect was underplayed and even stigmatized in most environments, but to me it was one of the reasons I fought to survive.”
- “Treat family and family planning issues with the same concern as for straight patients.”
 - LGBTQ Patient-Centered Outcomes, National LGBT Cancer Network, 2013
- “... there is never anything in [gay health resources] about prostate cancer ... they were supposed to be good on health ... on the HIV and AIDs and that, there was never a mention of ... prostate cancer at all.”
- “That's the thing, there is no resource, and I mean particularly for gay men, like gay men are as prone to prostate cancer as any other men ... there was nothing to say oh, I'll go to *that*, like there isn't a resource there actually.”
 - McConkey & Holborn, 2018



"Part-time employees are expected to work 24 hours a day.
Full-time employees are expected to work 48 hours a day."

The lie

Screening for sexual health issues takes
extra time and special training

A reliable *single* screening question:

- Are you having any sexual problems or concerns?
 - Easily added to any screening form
 - Easily replicated at each visit

Adding timeline qualifiers:

- Since you were in clinic last?
 - Lasting 3 months or more?
 - In the past year?
- Flynn et al, 2015

Expanded Sexual Health Clinical Screener

Flynn et al, 2015

- In the past 12 months, has there ever been a period of 3 months or more when you had any of the following problems or concerns?
 - ☐ You wanted to feel more interested in sexual activity
 - ☐ You had pain during or after sexual activity
 - ☐ You had difficulty having an orgasm
 - ☐ You felt anxious about sexual activity
 - ☐ You did not enjoy sexual activity
 - ☐ You had difficulty with erections (penis getting hard or staying hard)
 - ☐ Your vagina felt too dry
 - ☐ Some other sexual problem or concern
 - ☐ No sexual problems or concerns

Considerations

- Use of vague terms are not helpful
- Be clear on what sexual practices are *actually* being talked about
 - Kissing? Closed or open mouth?
 - Touch? External or internal?
 - Penetration? Oral, vaginal, rectal?
 - Body fluids? What ones? Why?
- What words?
- What language?
 - Written and web-based information in patient's language of choice?
 - Interpreter services *or* partner, family, friend...
- Trauma informed care
 - Ask about history of family, physical, medical, and/or sexual trauma
 - Transparency and consistency builds trust and safety
 - Collaborate on decisions
 - Allow timeline for informed choices
 - Offer trustworthy peer support
- You don't need to have the answers
- Share resources, make trustworthy referrals, follow up, ask again
- **Asking makes a difference.**

When I dare to be powerful – to use my strength in the service of my vision, then it becomes less and less important whether I am afraid.

- Audre Lorde (The Transformation of Silence into Language & Action) 1977

Resources

Sexual health tools and considerations
for your practice setting

Knowing when to use caution and when to welcome physical contact

- Chemotherapy, immunotherapy, radiation, and surgery create risks for patients and partners:
- Low blood counts
 - *Infection risk (white count <1000, ANC <500)*
 - *Bleeding risk (platelets <20,000, some risk <50,000)*
- Integrity of the mouth, gut, vagina, rectum, or skin
- Virus reactivation and/or infection susceptibility
- Pain or irritation that persists means stop and seek help
- No body fluid/sexual contact **for how long?**
- Barrier protection **for how long?**
- Contraception **for how long?**



Common intimacy and sexual health side effects

- Libido & desire alterations
- Vaginal/tissue dryness
- Menopausal symptoms
 - Premature
 - Reactivation
- Testosterone/hormone alterations
- Pelvic pain syndromes
- Dyspareunia
- Orgasm dysfunction
 - Anorgasmia
 - Pain with orgasm and/or ejaculation
 - Retrograde, premature, delayed ejaculation
- Erectile dysfunction
 - Softer erections
 - Decreased erection duration
 - Inability to become erect
- Urinary and/or bowel changes
 - Retention
 - Leakage or incontinence
 - Increased infection rates
- Fertility changes
 - Infertility
 - Need for delayed fertility
 - Need for contraception
- Body image changes
 - Actual body alterations
 - Body dysmorphia
 - Role changes
- Sensitivity changes
 - Chronic pain
 - Decreased sensitivity
 - Hypersensitivity
 - Touch, smells, noises
 - Feeling over-touched or medicalized
- Mental changes
 - Anxiety, depression, worry
 - Fear of becoming close/attached
 - PTSD, trauma reaction
- Fatigue

Treatments & Medications

Treatments

- Pelvic floor physical therapy
 - Effective
 - Insurance coverage
- Laser treatments
 - Costly, \$2500 +/-
 - 3 treatments, 6 weeks apart and then yearly
 - Works for some, not for others
 - No large studies, comparison studies between treatment modalities, or studies in patients with pelvic cancers

Counseling

- Individual, couples, supportive unit
- Telemedicine
- Support groups

Integrative Therapies

- Acupuncture
- Massage
- Mindfulness

Medications

- Flibanserin (Addyi)
 - Cautions: Pre-menopausal women, no alcohol, many medication interactions, low BP, liver concerns
- Hormones
 - Estrogen
 - Local: cream or gel, suppository, ring
 - Systemic: oral or transdermal
 - Progesterone
 - Topical, oral, transdermal
 - Testosterone
 - Topical, oral, injection
 - Selective estrogen receptor modulators (SERMS)
 - Human chorionic gonadotropin (HCG)
 - Dehydroepiandrosterone (DHEA)
- PDE-5 Inhibitors (Viagra, etc.)
- Antidepressants
- Analgesics
- Gabapentin
- Local anesthetics

Techniques & Tools

Techniques:

- Self-exploration before partner involvement
- Sensate focus
- Non-sexual touch partner touch
- Pre-intimacy expectations
- Discussion *away* from the bedroom
- Writing down hopes and desires (self, partner, independent and/or share)
- Planning for intimacy with enough time
- Letting each intimacy event 'stand alone' vs. expectations or complications from 'last time'
- Legitimization of non-penetrative sex

Tools:

- Dilators, dildos
 - Maintain or regain length and stretch of tissues
 - Helpful if pain with insertion or thrust
- Vibrators:
 - Internal or external use
 - Helps with relaxation, moisture and pleasure
 - Many shapes, sizes, types and materials
- Dental dams, surgical gloves

Lube and/or moisturizers:

- Water base ('go to')
- Oil, silicone, hybrid (option)
- Hyaluronic acid (short term)
- Xylocaine (spot treatment)
- CBD (works for some)

Making your own intimacy education tool kit

- Lubes
 - Water base
 - Standard (no additives) – Sliquid H2O, Yes
 - More viscous – Sliquid Sassy, Good Clean Love
 - 4% Lidocaine – Good Clean Love, Desert Harvest
 - Silicone base
 - Not for use with silicone toys, very slippery
 - Oil & Hybrid base
 - optional additions – more nuanced use
- Moisturizer with water base
 - Sliquid Satin, Ah! Yes, Blossom Organic
- Dilators – many size and composition options
 - Inspire silicone kit
- Vibrators – wide price range, shapes, sizes, vibration intensity
 - Internal and external use
 - Rechargeable (vs. battery) are best for kits
- Erection ring – variety of types
 - Something non-intimidating and easy to remove is best
 - Vacuum pump and chamber?
 - Sleeve?
- Sample books
- Handouts: pamphlets, book list, store list, website list, therapists, etc.

Stores and Web-Based Information

- **SheBop:** She Bop is a women-owned sex toy boutique in Portland, Oregon specializing in body safe products and education. 503-473-8018
<http://www.sheboptheshop.com/>
- **Shine:** A unique cancer specialties store with many books and products mentioned in this talk as well as compression garments and more. 206-606-7560 www.sccashine.org
- **Babeland:** Seattle based erotic toys and books. 206-328-2914
www.babeland.com
- American Cancer Society
www.cancer.org
- CANCERcare
<https://www.cancercare.org>
- Livestrong www.livestrong.org
- Oncofertility Consortium:
<https://oncofertility.msu.edu/>
- Stupid Cancer: All things AYA
<https://stupidcancer.org>
- TheCSPN: The Cancer Survivorship Provider Network www.thecspn.org
- The National LGBT Cancer Network
www.cancer-network.org
- Many oncology institutions have intimacy and sexuality resources and links on their web sites



Healthcare Providers

- **Providers in the know: Ask around!**
 - Docs, NP's, PA's, nurses in GYN, Gyn-Onc, Urology, Men's Health, and general practice, too
 - Psychologists, social workers, counselors, chaplains, pharmacists
 - Acupuncture, massage therapy, hypnosis, trauma work, physical therapy, movement therapy
- **Pelvic Floor Physical Therapy**
 - Up and down regulation for the core and pelvic floor. Helps with incontinence, pain, spasm, adhesions, and more.
- **Therapists/support Groups**
 - <https://therapists.psychologytoday.com/>
- **Sexuality Therapists**
 - <http://www.webmd.com/sex-relationships/features/what-does-sex-therapist-do>
 - <http://www.aasect.org/referral-directory>



Books: *for you and your patients*

- And In Health: A Guide for Couples Facing Cancer Together by Dan Shapiro
- Breaking the Silence on Cancer and Sexuality, A Handbook for Healthcare Providers by Anne Katz
- Gay and Bisexual Men Living with Prostate Cancer: From Diagnosis to Recovery by Jane Ussher, Janette Perz, et al
- Healing Sex: A Mind-Body Approach to Healing Sexual Trauma by Staci Haines
- Intimacy After Cancer: A Woman's Guide by Sally Kydd and Dana Rowett
- It's in the Bag and Under the Covers by Brenda Elsagher
- Making Love Again: Hope for Couples Facing Loss of Sexual Intimacy by Keith Laken
- Man, Cancer, Sex by Anne Katz
- Reproductive Health and Cancer in Adolescents and Young Adults by Gwendolyn Quinn and Susan Vadaparampil, Editors
- Saving Your Sex Life: A Guide for Men with Prostate Cancer by John Mulhall
- Sexual Intimacy for Women: A Guide for Same-Sex Couples by Glenda Corwin
- Sexuality and Fertility After Cancer by Leslie R. Schrorer
- Sexuality and Illness: A Guidebook for Health Professionals by Anne Katz
- The Monster Under the Bed: Sex, Depression, and the Conversations We Aren't Having by JoEllen Notte
- This Should Not Be Happening, Young Adults with Cancer by Anne Katz
- Woman, Cancer, Sex by Anne Katz

Tell Me

- Anna Swir (1909 – 1984)

Tell me, my dearest
now when I listen
to your heart beating,
when I drink from a little spring of warmth
in your neck,
when I look into you
as if you were transparent,
and see every thought of yours
and know
that you would die for me
were it necessary,
tell me now
whether we are the happiest
of all people
or the most unhappy.

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