

# **Symptom Management Guidelines: INTIMACY AND SEXUALITY**

MANAGEMENT OF CONCERNS | PLISSIT MODEL | RESOURCES | CONTRIBUTING FACTORS | APPENDIX

# Definition(s)

- **Intimacy:** Sharing of identity, mutual acceptance, closeness and reciprocated rapport more closely linked to communication than sexual function. Intimacy, like sexuality, is intrinsic to a sense of self.
- **Sexuality:** Encompasses sexual behaviors, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy, and reproduction. Is a complex phenomenon which encompasses our biological being, sense of self, and the way in which we relate to others.

## **Focused Health Assessment**

- Modify assessment to accommodate variations in patient age, gender, culture, sexual orientation and stage of illness
- Include patient's partner, as appropriate

# PHYSICAL ASSESSMENT

#### General

 Note mood, affect; cognitive status; general physical status

### **Hydration Status**

- Mucous membranes moist, dry?
- Skin turgor, capillary refill

## **Skin Integrity**

- Presence of wounds, surgical scars, degree of healing
- Presence of alopecia

#### **Abdominal Assessment**

 Abdominal distention, Abdominal and pelvic pain and tenderness

#### Range of Motion

With or without discomfort

#### Genitourinary

- Note any changes in continence or structure
  - For women: changes to vulvovaginal tissues (erythema, atrophy, sores/lesions, vaginal stenosis)
  - For men: changes to penis/testicles/scrotum (sores, lesions, painful ejaculation)

#### Weight

 Note any significant changes in weight gain or loss

#### **Functional Status**

Activity level/ECOG or PPS

### SYMPTOM ASSESSMENT

# \*Consider contributing factors

#### Normal

- Do you feel that your diagnosis has led to changes or difficulties in your sexual feelings or expression? (if so, in what way(s)?)
- How do you express your sexuality (before your diagnosis? Now?)

#### **Onset**

• When did the change(s) occur?

### **Provoking / Palliating**

- What do you believe is causing your difficulties?
- What makes it better? Worse?

# Quality

• Can you describe your concerns regarding sexuality and intimacy?

#### Severity

How bothersome are your concerns?

#### **Treatment**

Have you tried to do anything to address your concerns regarding sexuality and intimacy? Was this successful?

#### **Understanding / Impact on You**

- What aspects of your sexuality do you believe have been affected by your cancer or treatment (positive or negative)?
- How has this treatment/experience affected your relationship with your partner? Or your partner's sexuality?
- Have you talked to your partner about your feelings?

### Value

- How important is your sexuality to you?
- What do you think is responsible for the changes in your sexual life?
- What are your goals for intimacy and sexuality?
- Are you interested in expressing your sexuality now?

# Management of Concerns Related to Intimacy and Sexuality

# Goals

- Establish goals for sexuality and intimacy and expected outcomes with patient and if applicable, their intimate partner
- Restore optimal intimacy/sexual practices by reducing or eliminating contributing factor(s); provide symptom management as necessary
- Maintain optimal physical health to enjoy and engage in intimacy/sexuality
- Minimize risk of consequences resulting from changes in intimacy or sexuality

<b>Key Consideration</b>	S
Privacy	<ul> <li>Consider appropriate environment to raise sensitive topics</li> <li>Consider person's sense of personal privacy in relation to openly discussing this topic</li> </ul>
Beliefs and Values	Consider cultural beliefs and values that may impose constraints on discussing sexuality and intimacy; respect and/or negotiate these boundaries
Communication	<ul> <li>The nurse's role in intimacy/sexuality support is focused on communication:         <ul> <li>Raising the topic</li> <li>Assessing patient and if appropriate, their partner's concerns</li> <li>Encouraging open communication where patients and their partners can communicate honest feelings, concerns, fears, and preferences</li> <li>Validating their concerns and sharing with other healthcare professionals as appropriate</li> </ul> </li> <li>Think broadly about intimacy and sexuality and the meaning for patient and their partner (e.g. desire for closeness, affection, reproduction)</li> </ul>
Immunotherapy	Decreased libido, weight gain or loss, mood changes, fatigue, irritability or headaches can be a sign of endocrinopathy or an adrenal crisis brought on by immune medicated side effects of Immunotherapy. Refer to protocol specific algorithms and consult with physician.
Sexual Orientation	Openly and non-judgmentally explore the sexual orientation of the patient
Capacity for Sexual Activity or Desire	<ul> <li>A person's capacity and desire for sexual activity is very personal and individualized</li> <li>Explore goals and help the patient and their partner achieve their desires/mutual pleasure to the best of their ability.</li> <li>Patients and their partners may need assistance in accepting changes in patterns of desire and ability to engage in sexual activities. Do not minimize or overestimate these concerns.</li> </ul>
Patient Education: Birth Control and Fluid Protection	<ul> <li>Discuss the common sexual side effects from cancer treatments</li> <li>Prevent pregnancy while receiving chemotherapy or radiation treatment</li> <li>Speak with your healthcare provider to determine best option of birth control for you</li> <li>Use a barrier (e.g. condoms, dental dam) for first 48 hours after chemotherapy to avoid exposure to partner and consider regular use of barriers to protect against sexually transmitted diseases/infections</li> </ul>
Reproduction	<ul> <li>Discuss sperm banking and freezing embryos as necessary prior to cancer-treatment delivery</li> <li>Referral to fertility preservation specialist</li> </ul>

#### P-LI-SS-IT MODEL The four-step model guides the health professional through assessment and intervention where difficulties arise in intimacy and sexuality. The level of intervention should be matched with the intensity of the issue. **Giving Permission** Invite patient to discuss concerns and ask questions in a safe environment Validate concerns and dispel any myths and misconceptions (reinforce that cancer is not passed from person to person) May start conversation by normalizing the topic (e.g. many people with cancer often have questions about sexuality and sexual functioning. Do you have any concerns or questions that you would like to discuss?) Normalize broad definition of sexuality and intimacy (see definitions above) Encourage patient to communicate with partner about cancer and sexuality Give permission for patient and partner to engage in intimate and sexual activities Limited Provide basic information related to sexual functioning and the impact of illness and associated treatments on intimacy and sexuality Information Provide information regarding altering sexual practices in response to changes in physiology

	<ul> <li>and function</li> <li>Provide relevant patient education and community resources regarding sexuality and cancer</li> <li>See Resources and Referrals Section</li> </ul>
Specific Suggestions	<ul> <li>Assessment of the relationship may reveal concerns (emotional or psychological) and a referral to a counselor may assist.</li> <li>Ask what activities they have enjoyed doing together in the past. Encourage couple to sit on the couch or nap together, hold hands, hug, play games, or go on dates to build intimacy</li> <li>Sensate focus exercises can assist couples to rebuild intimacy without the pressure to have intercourse <i>Appendix A: Sensate Focus Exercises</i></li> <li>Encourage foreplay, mutual pleasuring, self-stimulation, use of sexual aids, alternatives to penetrative intercourse, and positioning to reduce discomfort and associated symptoms.</li> <li>Describe options for psychosocial and medical interventions to enhance sexual functioning</li> <li>Assessment for body image disturbances as a result of treatment or disease (i.e. breast enlargement, surgery, scars)</li> <li>Women:         <ul> <li>Vaginal dryness-water-based or silicone lubricants that are glycerin free. Vaginal estrogen cream as appropriate</li> <li>To help prevent shortening of the vagina after radiation therapy, encourage women to continue sexual intercourse during therapy as tolerated. Alternatively, women may use a vaginal dilator on a daily basis or as directed by radiation-oncologist. A water-soluble lubricant should be used for intercourse and dilator use. Link to instructions for dilator use</li> <li>Men:</li></ul></li></ul>
Intensive Therapy	When guidance requires expertise beyond the nurse's scope, referral should be made (for individual and/or couple) See Resources & Referrals Section

RESOURCES & REFERRALS	
Referrals	<ul> <li>Counselor</li> <li>Mental health professional</li> <li>Sydney Thomson, MD,FR, CFC (gynecologist specializing in female sexuality) (physician specialized in supporting sexual dysfunction, available in lower mainland through referral)</li> <li>Sex therapist</li> <li>Reproductive endocrinologist</li> <li>Look Good Feel Better program <a href="http://www.lgfb.ca/en/">http://www.lgfb.ca/en/</a></li> <li>BC Center for sexual medicine – physician referral (both for men and women)</li> <li>BC Center for vulvar health – 2 clinics for cancer patients.</li> <li>Reproductive endocrinologist?</li> </ul>
Resources in BC	<ul> <li>BC Association For Marriage and Family Therapy: <a href="http://www.bcamft.bc.ca/">http://www.bcamft.bc.ca/</a></li> <li>BC Psychological Association: <a href="http://www.psychologists.bc.ca/">http://www.bc.ca/</a></li> <li>BC Association of Registered Clinical Counsellors: <a href="http://www.bc-counsellors.org/">http://www.bc-counsellors.org/</a></li> <li>BC Centre for Disease Control Smart Sex Resource: <a href="http://smartsexresource.com/">http://smartsexresource.com/</a></li> <li>Fertile Future: <a href="https://fertilefuture.ca/">https://fertilefuture.ca/</a></li> </ul>
Patient Education	<ul> <li>Canadian Cancer Society:         <ul> <li>Sexuality and Cancer Booklet:</li></ul></li></ul>

	etc. Located in Patient Handouts <a href="http://www.bccancer.bc.ca/health-info/coping-with-cancer/emotional-support/managing-stress">http://www.bccancer.bc.ca/health-info/coping-with-cancer/emotional-support/managing-stress</a> <ul> <li>Vaginal Dilator Patient Education Resource (Care for women after radiation to the pelvis)</li> </ul>
Immunotherapy	<ul> <li>Immunotherapy Alert Card</li> <li>Please refer to protocol specific algorithms to guide management of immune mediated side effects.</li> </ul>
Health Professional Info	Sexuality and Prostate Cancer – Dr. Anne Katz <a href="https://www.youtube.com/watch?v=fZLOR7bLHa4">https://www.youtube.com/watch?v=fZLOR7bLHa4</a> Sexuality after prostate cancer – Reanne Booker     Part 1: <a href="https://www.youtube.com/watch?v=AqCTLh84tAs">www.youtube.com/watch?v=AqCTLh84tAs</a> Part 2: <a href="https://www.youtube.com/watch?v=pz1IGd1nzHM">www.youtube.com/watch?v=pz1IGd1nzHM</a>

Contributing Factors		
Cancer Treatment Related	<ul> <li>Surgery         <ul> <li>Depending on surgical site, may result in infertility, altered sexual function and/or alterations in body image (e.g. prostate surgery, testicular surgery, hysterectomy, oophorectomy, vaginectomy, vulvectomy, abdominoperineal resection, mastectomy)</li> <li>Chemotherapy</li> <li>Can cause temporary or permanent loss of ovarian and testicular function resulting in infertility for both, and premature menopausal symptoms for women</li> <li>Sensory neuropathy in the genitals</li> </ul> </li> <li>Radiation therapy         <ul> <li>Radiation to the pelvic area can cause vascular or nerve damage which impairs sexual functioning either temporarily or permanently</li> <li>Women: Vaginal atrophy, stenosis, fibrosis, or shortening, amenorrhea, painful intercourse, decreased lubrication, ovarian failure, premature menopause, diminished libido</li> <li>Men: Decreased testosterone secretion, testicular aplasia, diminished semen volume, ejaculatory pain, diminished libido</li> </ul> </li> <li>Hormonal Agents         <ul> <li>May result in weight loss or gain, menopausal symptoms, diminished libido, erectile dysfunction, masculinization in women, emasculation in men</li> </ul> </li> <li>Immunotherapy - Checkpoint Inhibitors         <ul> <li>Diminished libido, mood changes, weight gain or loss or fatigue due to immune mediated side effects.</li> </ul> </li> <li>Biologic Agents         <ul> <li>Mucous membrane dryness, diminished libido, erectile dysfunction, pelvic pain</li> </ul> </li> </ul>	
Symptoms	<ul> <li>Physical symptoms can alter comfort, interest, desire, and ability to engage in sexual activities (e.g. fatigue, pain, dyspnea, nausea)</li> <li>Psychological distress (e.g. anxiety, depression, fear, uncertainty)-can decrease one's energy, ability to concentrate and relax</li> <li>Changes in bowel or bladder functioning (e.g. ostomy, climacturia)</li> <li>Changes in mobility and Range of motion- may inhibit ability to comfortably engage in sexual positions</li> </ul>	
Side Effects of Medications	<ul> <li>Many medications used for symptom management (e.g. some anti-emetics, opioids, anxiolytics, antidepressants, antihypertensives, antihistamines) have sedative effects, sense dulling properties, reduce libido and/or interfere with erectile function</li> <li>Vaginal dryness and other menopausal symptoms</li> </ul>	
Body Image Disturbance	<ul> <li>Related to weight changes, hair loss, surgical scarring, changes in elimination patterns (e.g. ostomies, catheters)</li> </ul>	
Partner Concerns	<ul> <li>Emotional distress, fears about hurting patient</li> <li>Role shifting/confusion-intimacy can be difficult when partner has various roles- caregiver, partner, lover.</li> </ul>	

# Consequences

- Altered perceptions of body image, self-esteem, self-confidence
- Psychological distress, feelings of isolation and/or alienation
- Changes in relationships

Aversion or reluctance to engage in activities of sexual/intimate expression

# Appendix A: Sensate Focus Exercises (Sexual Health Counseling & Cancer – IPODE April 8, 2010)

Definition	Definition		
<b>Sensate Focus Exercises</b> : Series of exercises for couples that encourage each partner to give and receive pleasurable touch while paying attention to their sensual experience of receiving and giving touch			
Stage I	<ul> <li>Each partner takes turns touching each other's body (touching breasts, genitals and intercourse are off limits to start)</li> <li>Encouraged to suspend judgments and expectations</li> <li>Directed to focus their awareness on sensations</li> <li>Partner who is touching is to do so based on what interests them</li> <li>Partner who is the receiver lies on back and receives touch for 15 minutes then receives touch on back of body for 15 minutes; after 30 minutes partners switch roles</li> <li>Encourage couples to be as silent as possible however to let their partner know verbally or non-verbally if any touch is uncomfortable</li> <li>At end of experience, partners give each other specific feedback (3 things enjoyed and 1 thing they would change for next time)</li> </ul>		
Stage II	<ul> <li>Touching now includes breasts and genitals (intercourse off limits)</li> <li>Start with general body touching first</li> <li>As in Stage I, emphasis on awareness of sensations and partners take turn touching and receiving for 15 minutes on front and back</li> <li>Non-verbal communication (receiver places hand on partners hand to indicate if they want a change in pressure, pace, or area)</li> <li>At end of experience, partners give each other specific feedback (3 things enjoyed and 1 thing they would change for next time)</li> </ul>		
Stage III	Couples take turns touching and receiving but can now progress to helping each other experience orgasm through oral or manual stimulation		
Subsequent Stages	Couples slowly progress towards intercourse		

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