Psychosocial Sexual Health Interventions in Male and Female Cancers

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What is Cancer Survivorship?

- Survivorship focuses on the health and life of a person with cancer from diagnosis until the end of life.
- It covers the physical, psychosocial, and economic issues of cancer, beyond the diagnosis and treatment phases.
- Survivorship includes issues related to the ability to get health care and follow-up treatment, late effects of treatment, second cancers, and quality of life.
- Family members, friends, and caregivers are also considered part of the survivorship experience.

1996 Office of Cancer Survivorship

Mission:

• to enhance the quality and length of survival of all persons diagnosed with cancer

• to minimize or stabilize adverse effects experienced during cancer survivorship

• to support research that both examines and addresses the long- and short-term physical, psychological, social, and economic effects of cancer and its treatment among pediatric and adult survivors of cancer and their families
Institute of Medicine Recommendations

• Supportive care is needed to address survivorship issues
• Cancer recurrence and new cancers
• Treatment-related long-term effects
• Psychosocial aspects, including mental health, sexual health, relationships, caregiver needs, finances, etc.
  • Develop quality of survivorship care measures
  • Use evidence based guidelines
  • Increase funding support for survivorship research
Selected Cancer Survivorship Measures

- **Quality of Life (QOL)**
  - Functional Assessment of Cancer Therapy Scale – FACT (Cella, et al., 1993)
  - Expanded Prostate Cancer Composite Index - EPIC (Wei, Urology, 2000)
  - Bladder Cancer Index - BCI (Gilbert, J Urology, 2010)

- **Distress**
  - Distress Thermometer (Donovan, Psycoconc, 2014)

- **Cancer Communication**
  - Protective Buffering Scale (Manne, Cancer Res Ther & Control, 1999)

- **Relationship Assessment**
  - The Dyadic Adjustment Scale - DAS (Spanier et al., J Marr & Fam, 1976)

- **Patient Reported Outcome Measure Information System (PROMIS)**
  - a set of person-centered measures that evaluates and monitors physical, mental, and social health in adults and children (Cella et al., J Clin Epid, 2007)

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The Distress Thermometer

First please circle the number (0-10) that best describes how much you have been experiencing in the past week including today. Be sure to check a YES or NO for each.

- YES
- NO

Practical Problems
- Child Care
- Housing
- Insurance/Financial
- Transportation
- Work/school

Child Problems
- Feeding
- Toilet training

Family Problems
- Dealing with children
- Dealing with partner
- Dealing with close friends/relatives

Emotional Problems
- Depression
- Fears
- Hostility
- Sadness
- Sorrow
- Less interest in usual activities
- Ireland physical health concerns

Other problems

Physical Problems
- Fatigue
- Feeling cold
- Sweating
- Eating
- Fatigue
- Feeling full
- Pains
- Getting around
- Indigestion
- Memory/concentration
- Mouth sores
- Nausea
- Nose dry/tongue
- Skin
- Cold
- Itchy
- Sleep
- Tingling in hands/feet
Cancer survivorship guidelines

American Cancer Society/American Society of Clinical Oncology Breast Cancer Survivorship Care Guideline

Carolyn D. Runowicz, MD1; Corinne R. Leach, PhD, MS, MPH2; N. Lynn Henry, MD, PhD2;
Karen S. Henry, MSN, ARNP, FNP-BC, AOCNP3; Heather T. Mackey, RN, MSN, ANP, AOCNP1;
Rebecca L. Cowens-Alvarado, MPH2; Rachel S. Cannady, BS2; Mandi L. Pratt-Chapman, MA6; Stephen B. Edge, MD, FACSF7;
LaMonte, MD8; atricia A. Ganz, MD9

American Cancer Society Prostate Cancer Survivorship Care Guidelines

Ted A. Skolarus, MD, MPH1; Andrew M.D. Wolf, MD2; Nicole L. Erb, BA3; Durado D. Brooks, MD, MPH5;
Brian M. Rivers, PhD, MPH1; Willie Underwood III, MD, MPH, MScF1; Andrew L. Salter, MD1; Michael J. Zelefsky, MD6;
Jenny B. Aragon-Chaming, MD2; Susan F. Slowin, MD, PhD10; Daniela A. Wittmann, PhD, MSW, COT11; Michael A. Hoot, PhD12;

American Cancer Society Head and Neck Cancer Survivorship Care Guideline

Ezra W. Cohen, MD1; Samuel J. LaMonte, MD, FACS2; Nicole L. Erb, BA3; Kerry L. Beckman, MPH, CHES4;
Nader Sadeghi, MD5; Katherine A. Hutchison, PhD6; Michael D. Stubblefield, MD7; Dennis M. Abbott, DDS8;
Penelope S. Fisher, MS, RN, CORLN9; Kevin D. Stein, PhD10; Gary H. Lyman, MD, MPH, FASCO, FACP11;

American Cancer Society Colorectal Cancer Survivorship Care Guidelines

Khaled El-Shami, MD, PhD1; Kevin C. Oeffinger, MD2; Nicole L. Erb, BA3; Anne Willis, MA4; Jennifer K. Bretsch, MS, CPHQ5;
Mandi L. Pratt-Chapman, MA6; Rachel S. Cannady, BS7; Sandra L. Wong, MD, MS8; Johnie Rose, MD, PhD9;
April L. Barbour, MD, MPH, FACP10; Kevin D. Stein, PhD11; Katherine B. Sharpe, MTS12; Durado D. Brooks, MD, MPH13;
Rebecca L. Cowens-Alvarado, MPH14

No guideline for sexual health care in cancer survivorship!
Research is Developing Slowly

- Most research done in breast and prostate cancer
- It is important to do research on survivors of childhood cancer
- Emerging studies on the impact of cancer on sexuality in patients treated for colorectal and head and neck cancer
- Insufficient data on the cultural context of the impact of cancer on sexuality
- We mostly have observational studies, few intervention studies
- Lack of dedicated funding to sexual health issues for cancer survivors
What We Have Learned from Observational Studies

• Men treated for prostate cancer are sad, feel a loss of masculinity, lose confidence in interactions with others (Bokhour, J Gen Int Med, 2001, Hedestig, Acta Oncol, 2005, Wall & Kristjanson, Nurs Inq, 2005)

• Women treated for breast cancer experience embarrassment, fear of rejection, anxiety, loneliness and isolation (Pillai-Friedman & Ashline, Sex Rel, 2014, Dizon, The Oncol, 2014)

• Patients treated for colorectal cancer experience decrease in sexual quality of life, increase in depression and distress regarding their body image. Body image distress is higher for women than for men (Reese et al., Supp Care Ca, 2018)

• Partners are distressed about the loss of sexual relationships (Tanner, Am Coll Nurs Midw, 2011, Bruun, Urol Nsg, 2011, Dizon, The Oncol, 2014)

• Couples struggle, often unsuccessfully, to maintain sexual intimacy (Sanders, Clin J Onc Nsg, 2006, Gilbert et al., Cult, Health, Sex, 2013, Galbraith et al., Clin J Onc Nsg 2012, Rivers et al., J Canc Ed, 2012)

• Young survivors report physical discomfort (vaginal dryness/tightness, testicular over-sensitivity), sense of insecurity about having to explain cancer, anxiety about fertility status (Frederick, Ped Blood Cancer, 2016)
Changing Sexual Paradigm after Cancer Treatment

Sexual function for many patients does not return to baseline

Patients and partners grieve the loss of familiar sexual interactions

Spontaneous vs cultivated sexual activity becomes key
- Replacing spontaneity with anticipation, fantasy
- Planned sexual encounters, erotica, sex toys
Grief as a Part of a Sexual Encounter

Wittmann et al., J Sex and Marital Ther, 2011
Psychosocial Interventions Development

• Interventions have focused on a variety of outcomes
  • Sexual function improvement
  • Increased knowledge of sexual side-effects and rehabilitation
  • Couple communication/relationship satisfaction
  • Use of sexual aids

• Interventions have used a variety of approaches
  • Mindfulness-based cognitive behavior therapy
  • Psychoeducation
  • Sexual goal setting
  • Acceptance and commitment therapy
  • Intimacy enhancement

• What are sexual health needs of cancer survivors?
• Which areas need to be targeted?
• What are reasonable outcomes to pursue?
Psychosocial Interventions in Breast and Gynecological Cancers

- **Mindfulness-based Cognitive Behavioral Sex Therapy**, body awareness education and support for sexual rehabilitation improved sexual function and lowered anxiety in a study with 19 women with breast cancer (Bober, et al., J Ca Surv Res, 2019, Bober et al., Cancer, 2018)

- A randomized controlled pilot study of **Intimacy Enhancement Therapy** (IET) vs supportive therapy demonstrated that the IET improved sexual function and relieved distress in participating women with breast cancer (Reese et al., J Psychosoc Onc, 2018)

- Online vs online+in person education about sexual side-effects and treatment improved sexual outcomes for women with breast and gynecological cancers (Schover et al., JNCCN, 2013)

- Online program that included **cognitive behavioral intervention** for patients and partners resulted in both patients and partners improved sexual satisfaction (Humel et al., J Sex and Marital Ther, 2019)

- SPIRIT program – **peer counseling** for African American breast cancer survivors resulted in 66% of participants finding the intervention helpful (Schover et al., 2012)
Psychosocial Interventions in Prostate Cancer

- **Acceptance and Commitment Therapy** with individual men increased their use of pro-erectile aids (Nelson, J Sex Med, 2019)

- **Couple-based sexual health counseling** by counselors or nurses or peers increased use of pro-erectile aids (Titta et al., J Sex Med, 2006, Chambers et al., Psychoonc, 2013)

- **Couple-based psychoeducational intervention** led to partners’ acceptance that sex can be satisfying even if the man had erectile dysfunction (Wittmann et al., 2013) and helped reduce men’s bother about sexual dysfunction after treatment (Robertson, Sex Med, 2016)

- **Couple-based pre-treatment education** for patients who were about to undergo radical prostatectomy and their partners helped them develop realistic expectations of functional outcomes (Paich et al., Urology, 2016)

- **Couples who received pre-treatment education** about sexual dysfunction and rehabilitation before the men were started on hormonal therapy (ADT) were more sexually active than couples who did not (Walker et al., Cont Clin Trials, 2013)
Psychosocial Interventions in Other Cancers

- **Telephone support** (4 sessions) resulted in higher sexual function and decrease in distress in sexually active women with rectal and anal cancers (DuHamel et al., J Cancer Surv, 2016)

- Protocol to address sexual health issues and fertility distress in young adult survivors of cancer (Lampic et al., BMC-Cancer, 2019)
Psychosexual Programs Embedded in Usual Prostate Cancer Care

Princess Margaret Cancer Center- Toronto
Psychologist and sexual health counselor

University of Michigan Ann Arbor
Nurse practitioners and certified sex therapists

Ongoing use of pro-erectile therapy

Erections firm enough for penetration

Matthew A et al., AUA 2018

Quality of Life and Satisfaction Among Prostate Cancer Patients Followed in a Dedicated Survivorship Clinic
Scott M. Gilbert, MD, MS1, Rodney L. Dunn, MS2, Daniela Wittmann, PhD3,4, Jeffrey S. Montgomery, MD3, John M. Hollingsworth, MD, MPH5, David C. Miller, MD, MPH2,6,7, Brett K. Hohenfeld, MD, MS1,2, and James E. Montie, MD3,4
Cancer, 2014

TABLE 2. Mean QOL and Satisfaction Scores in “Before” and “After” Groups

<table>
<thead>
<tr>
<th></th>
<th>Baseline</th>
<th>6 Months</th>
<th>1 Year</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Before</td>
<td>After</td>
<td>P</td>
</tr>
<tr>
<td>Urinary incontinence</td>
<td>94.1</td>
<td>94.5</td>
<td>.70</td>
</tr>
<tr>
<td>Urinary irritation</td>
<td>96.2</td>
<td>96.5</td>
<td>.95</td>
</tr>
<tr>
<td>Sexual function</td>
<td>77.6</td>
<td>71.9</td>
<td>.30</td>
</tr>
<tr>
<td>Bowel function</td>
<td>96.0</td>
<td>96.2</td>
<td>.52</td>
</tr>
<tr>
<td>Hormone function</td>
<td>91.3</td>
<td>94.0</td>
<td>&lt;.01</td>
</tr>
</tbody>
</table>

Satisfaction with outcome | 89.2  | 93.1  | <.01  |
Satisfaction with manner/skill | 91.1  | 95.4  | <.01  |
Satisfaction with information | 88.1  | 94.8  | <.01  |
Satisfaction with access | 89.3  | 93.1  | <.01  |
Barriers to Access to Psychosexual Care and Research

- Lack of trained healthcare providers (Frederick, Ped Blood Cancer, 2018)
  - Pediatric oncology clinicians, when interviewed, described lack of knowledge/experience, lack of resources/referrals, low priority, parents/family, patient discomfort, clinician discomfort, time, and lack of rapport

- Lack of investment in psychosexual support by cancer centers and cancer treatment practices

- Expense of sexual health support and distance for patients to access available resources

- Challenges to recruitment for research (Reese et al., Transl Beh Med, 2018)
  - Time commitment
  - Partner does not agree
Telemedicine Increases Access to Sexual Health Support in Cancer

Leslie Schover, PhD
Founder
Telemedicine Increases Access to Sexual Health Support in Cancer

**Personalized approach to symptom management**

**TrueNTH Couples sexual recovery**

**TrueNTH SHAREClinic**

Hawley, Skolarus et al., Trials, 2016

Wittmann et al., BMC-Cancer, 2017

Matthew et al., Funded by the Movember Foundation
Erectile Dysfunction & Penile Rehabilitation

What is erectile dysfunction? Erectile dysfunction, or ED, is when you can’t get or keep an erection firm enough for intercourse.

When will ED start, and what will happen over time?
- It depends on your health.
- ED can happen in₁₀painful manner outside of any ED.
- It can happen in people with no history of ED.

Prostate cancer surgery:
- Erectile dysfunction starts right away in many men.
- Sexual activity declines within weeks of starting hormone therapy.

Advantages over ED may start gradually and improve in some cases.
- You may have sex with your partner without affecting your sexual performance.
- You may have sex with your partner without affecting your sexual performance.
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- You may have sex with your partner without affecting your sexual performance.

Sexual Function Aids for Women

It’s important to address sexual health needs of both men with cancer and their partners.

Menopause and Sexual Health
- Menopause can cause many symptoms, including changes in sexual desire.
- It’s important to discuss this with your doctor before starting menopause-replacement therapy.
- Menopause-related changes in sexual desire may lead to less frequent or less satisfying sexual activity.
- Maintaining sexual health includes restoring moisture and stretch to the vaginal area.

Strategies for Female Sexual Health
- Sexual activities are an important part of women's sexual health.
- These include vaginal dryness, aches, or burning sensations.
- There are specific strategies to help with these issues. For example:
  - Keep your body warm.
  - Use lubricants.
  - Avoid caffeine.

Feeling Grief During Sex
- A person with ED may feel “guilty” about sex or relationships with cancer.
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- A person may feel “guilty” about sex or relationships with cancer.

How do you work through grief?
- There are many ways to work through grief, including:
  - Talking about your feelings with others.
  - Joining support groups for people who have undergone prostate cancer surgery.
  - Listening to music or other forms of entertainment.
  - Keeping a journal or writing letters to yourself.

About your treatment surgery
- Surgery works by removing the cancer from your body.
- During surgery, your surgeon removes your prostate.
- The prostate is the gland that surrounds the urethra and helps control the flow of urine.

Wittmann, Bober et al., 2019
Sexual Wellbeing

After prostate cancer treatment, changes to your sex life can be hard to accept. The good news? These changes are often temporary and can be improved. It will take work to get back on track, but being open and willing to try new things will make a difference.
Take Home Points

• Psychosocial interventions are showing promise, but are still evolving – they are not implemented.

• Healthcare providers should know the impact of cancer on sexuality.

• Healthcare providers are best positioned to begin the conversation and to point to available resources.

• Partners should be included in the conversation because patients’ sexual problems affect them, too.

• It is important for patients to learn that their sexual recovery often does not mean return to baseline.

• Education about the sexual side-effects of treatment and rehabilitation is best offered before treatment begins and repeated regularly so as to help modify expectations and avoid shock afterwards.

• The emotional aspects of the adjustment to the sexual changes should be normalized to reassure the patient (and partner) that feelings of loss and grief are to be expected.
By Addressing Cancer Patients’ Sexual Concerns, You Will Automatically Improve their Quality of Life
Thank You

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