

A microscopic image showing several chromosomes in various stages of division, rendered in shades of blue and purple against a black background. The chromosomes are elongated and have distinct centromeres and arms.

Body Image and Sexual Health

Ann H. Partridge, MD, MPH

Vice Chair and Professor, Medical Oncology

Director, Adult Survivorship Program

Director, Program for Young Women with Breast Cancer

Dana-Farber Cancer Institute



Dana-Farber
Cancer Institute

Disclosures

- UpToDate- royalties as co-author of Breast Cancer Survivorship section



Body Image and Sexual Health after Cancer

- Two common and potentially burdensome issues among cancer survivors
- 40–95% of all survivors report distressing sexual side effects
 - >50% of young adults report problems in >two areas of sexual function
- Although sexual problems are common, compared to healthy controls, survivors still have significantly more challenges



Body Image and Sexual Health are Intertwined Especially in Breast Cancer

- Grooming and appearance are integral aspects of sexuality
- Breast cancer treatment causes substantial body and body image changes:
 - Loss of breast/breast tissue(s), scars, skin changes, lymphedema
 - Pain
 - Loss of sensation and mobility
 - Hair loss
 - Hormonal changes
 - Weight changes



Body Image after Breast Cancer

- Body image is a multidimensional picture an individual forms in her mind of her own body, with associated characteristics including expression of emotions, imitation, identification, beauty, and social aspects
- Three areas are characteristics of the complex concept of body image in women who have been treated for breast cancer:
 - affective (feeling feminine, feeling attractive)
 - behavioral (avoiding people because of appearance)
 - cognitive (satisfaction with appearance, or with scar)



Body Image after Breast Cancer

- Extensive literature documents body image after breast cancer, much of which focuses on the newly diagnosed coping with mastectomy and adjuvant treatments
- Body image dissatisfaction related to decreased quality of life
 - Younger patients, patients with higher BMI report more body-image distress
 - Breast conserving therapy, immediate reconstruction & autologous tissue-based more favorable body-image outcomes
- 50%–75% younger survivors report poor body-image satisfaction



Body Image after Breast Cancer

- Longitudinal data show the relationships between depression, sexual difficulties, body image distress, and for some, marital difficulties
- There are limited data from lower resource but that which is available suggests difficulties of greater severity and diffuse effects



Base-Line Quality-of-Life Assessment in the National Surgical Adjuvant Breast and Bowel Project Breast Cancer Prevention Trial

This was a PREVENTION Trial

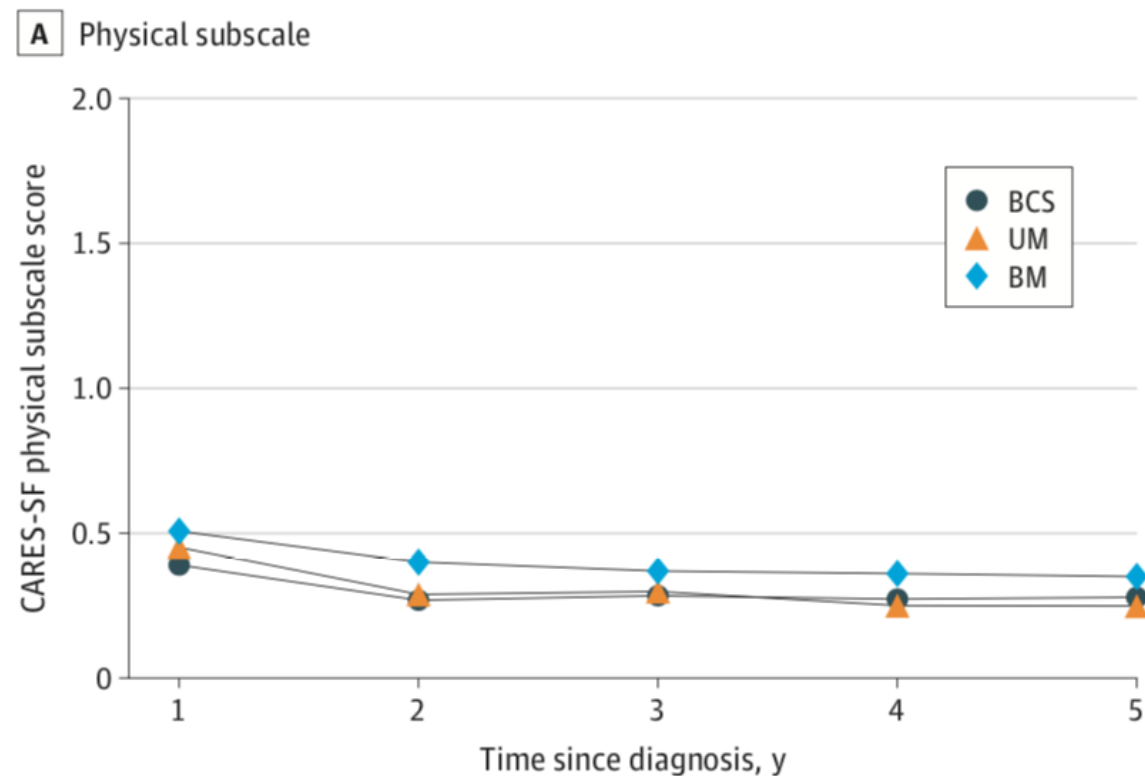
*Patricia A. Ganz, Richard Day, John E. Ware, Jr., Carol Redmond, Bernard Fisher**

Table 2. Ten most frequently reported symptoms

Symptom	% overall	Age, y		
		% 35-49	% 50-59	% ≥60
Unhappy with appearance of body	58.7	59.8	60.8	53.2
Headaches	56.5	67.0	57.4	41.6
Joint pains	49.3	38.6	52.4	60.3
General aches and pains	48.9	43.5	53.3	51.5
Muscle stiffness	41.8	34.6	45.3	47.8
Breast sensitivity	40.9	58.3	35.3	23.8
Early awakening	39.1	31.4	42.8	45.3
Forgetfulness	38.2	29.9	53.6	47.5
Hot flashes	34.6	26.0	53.6	26.4
Swelling of hands and feet	28.6	26.8	29.7	29.8

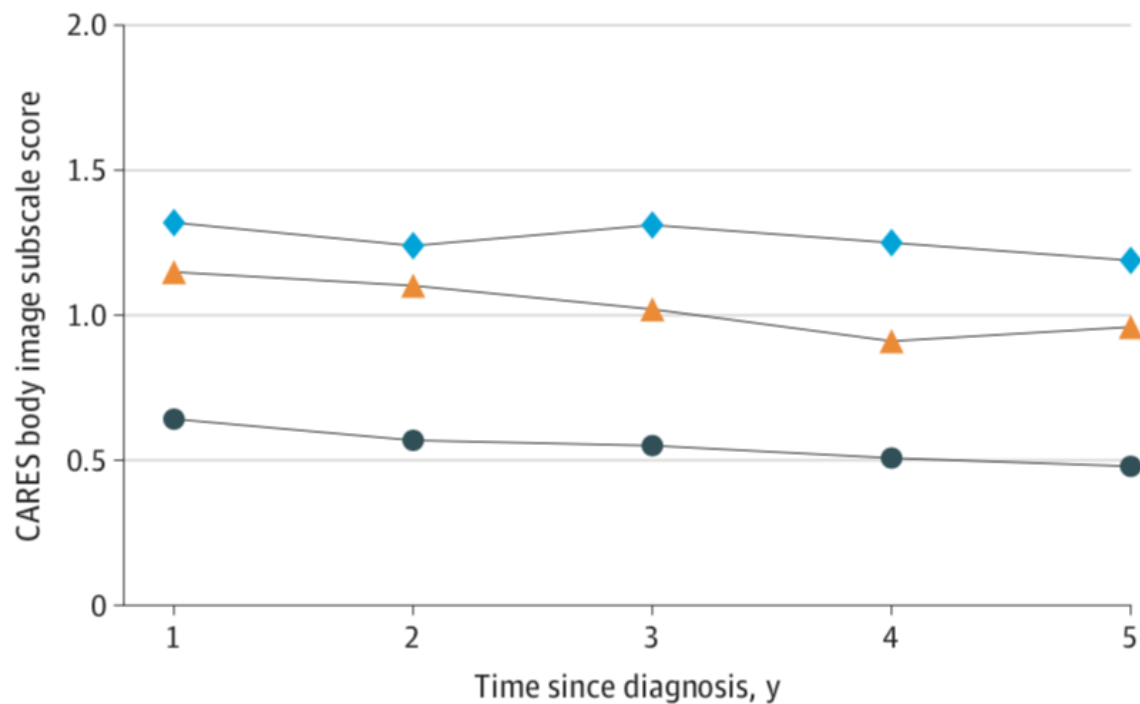
Body Image and Sexual Health in Young Breast Cancer Survivors in YWS

- Among 826 eligible women in the Young Women's Breast Cancer Study (YWS), all age ≤ 40 at dx:
 - 254 had breast-conserving surgery (BCS)
 - 197 unilateral mastectomy (UM)
 - 375 bilateral mastectomy (BM)
- Enrolled between 2006-2016 and followed for this analysis out 5 years
- CARES physical, body-image and sexual subscales: higher scales indicate worse outcomes

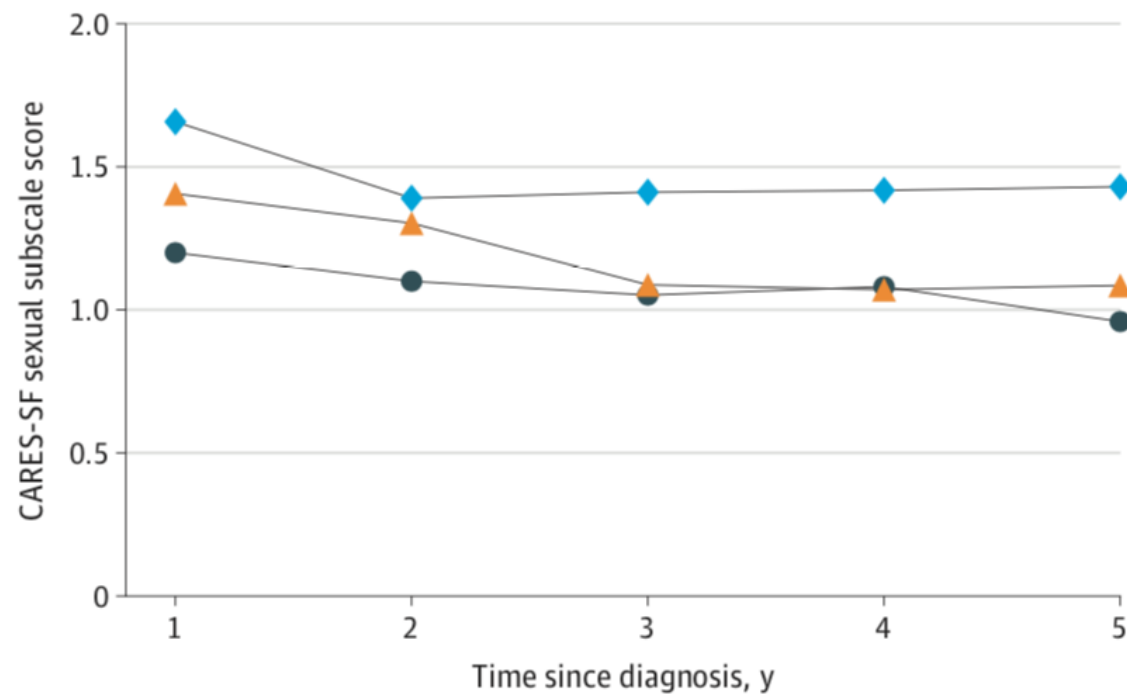


Body Image and Sexual Health in YWS

B Body image subscale



C Sexual subscale



Body Image in YWS by Surgery

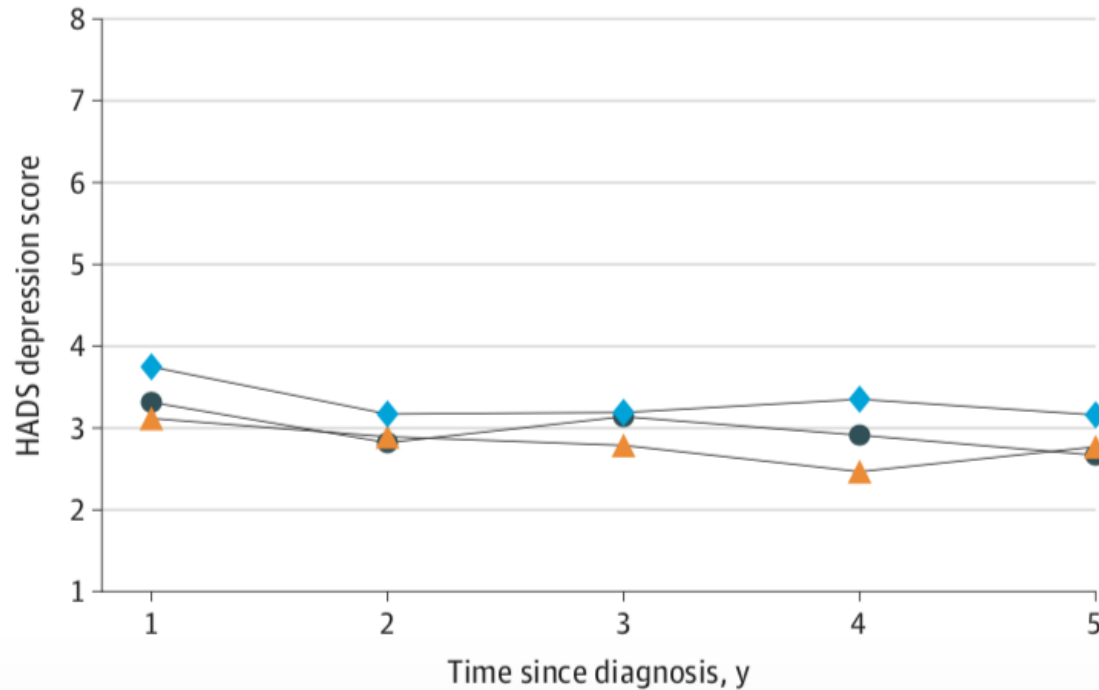
	Discomfort with body changes, %	χ^2 P value	Embarrassment showing body, %	χ^2 P value	Discomfort showing scars to others, %	χ^2 P value
Year 1 (n = 826)						
BM/recon	40.6	.002	33.7	<.001	36.0	<.001
BM/no recon	43.8		43.8		50.0	
UM/recon	34.6		24.1		27.8	
UM/no recon	28.3		30.0		28.3	
BCS	25.2		12.0		9.6	
Missing, No.	11		13		12	
Year 5 (n = 599) ^a						
BM/recon	27.0	.002	30.5	<.001	34.6	<.001
BM/no recon	52.2		52.2		52.2	
UM/recon	21.9		22.9		29.2	
UM/no recon	31.9		23.4		21.3	
BCS	17.9		9.7		9.7	
Missing, No.			1			

Sexual Health in YWS by Surgery

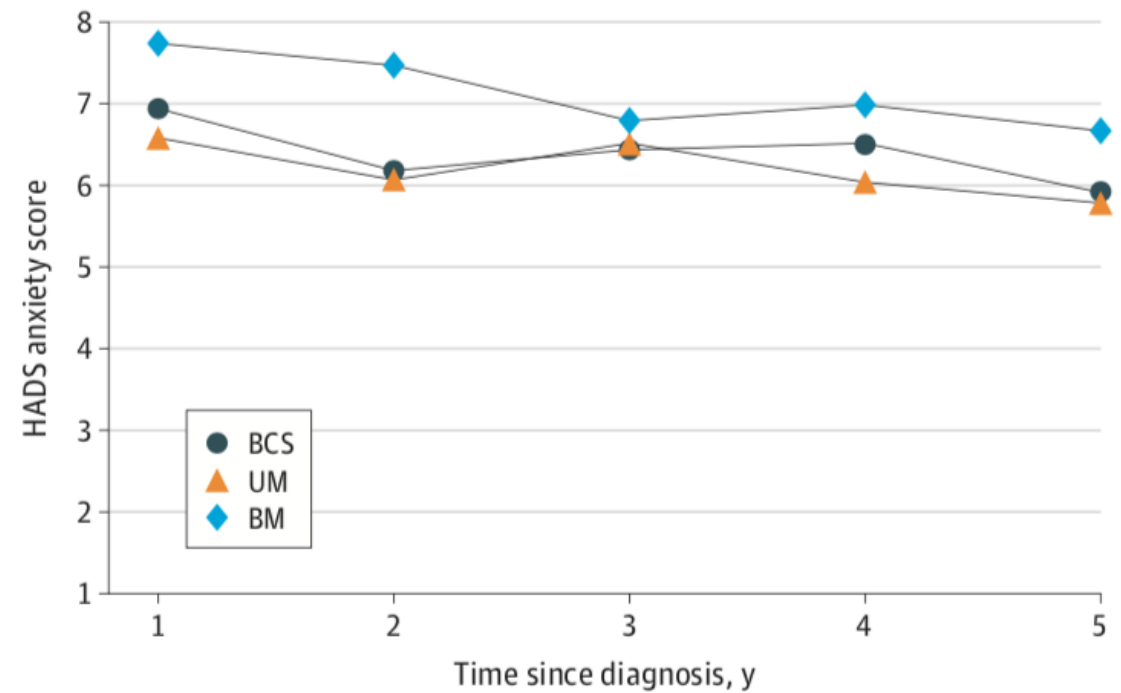
Variable	Perceived sexual unattractiveness, %	χ^2 P value	Disinterest in sex, %	χ^2 P value	Decreased sexual activity frequency, % ^a	χ^2 P value
Year 1 (n = 826)						
BM/Recon	43.8	.002	47.8	<.001	43.9	.02
BM/No Recon	56.3		46.9		65.2	
UM/Recon	41.7		37.6		43.6	
UM/No Recon	45.0		36.7		36.3	
BCS	29.9		29.1		34.3	
Missing, No.	11		11		2	
Year 5 (n = 599) ^b						
BM/Recon	34.8	<.001	44.6	<.001	41.8	.36
BM/No Recon	52.2		60.9		63.2	
UM/Recon	25.0		27.1		39.1	
UM/No Recon	25.5		32.6		39.0	
BCS	18.8		28.7		39.1	
Missing, No.	5		9		8	

Body Image and Sexual Health in Young Breast Cancer Survivors

B Depression score



A Anxiety score



What can be done to help with Body Image?

- Choose surgery wisely, encourage reconstruction if mastectomy
- Advise and support regarding risks of weight gain and inactivity through treatment, optimizing diet and exercise through and beyond treatment
- Refer for behavioral therapy





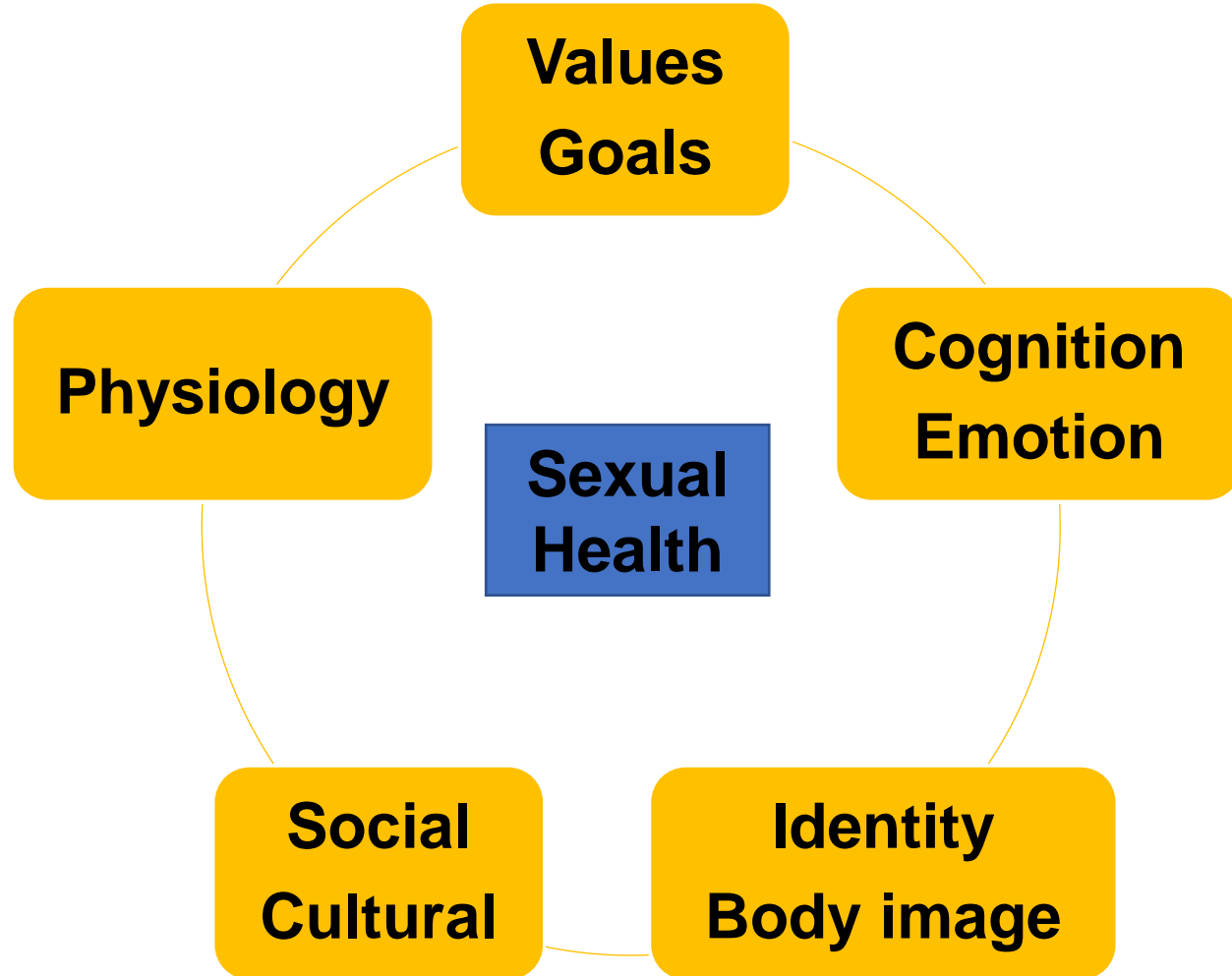
Reducing Body Image–Related Distress in Women With Breast Cancer Using a Structured Online Writing Exercise: Results From the My Changed Body Randomized Controlled Trial

Kerry A. Sherman, Astrid Przewdziecki, Jessica Alcorso, Christopher Jon Kilby, Elisabeth Elder, John Boyages, Louise Koelmeyer, and Helen Mackie

- My Changed Body single session, web-based psychological writing intervention (n=149) vs. expressive writing control (n=155)
- Significantly less body image distress and greater body appreciation and self-compassion
- Therapeutic effects were maintained at 1 and 3 months after intervention



Sexual Health



- Life-affirming human experience across the lifespan
- A multi-dimensional experience (Physical, Psychological, Interpersonal)
- Always in context

Sex, Cancer & Quality of Life (QoL)

- Recognized by WHO (2006): Satisfying sexual function is a health-related QOL issue and a fundamental human right
- Sexual dysfunction associated with:
 - Anxiety / depression
 - Low self-esteem / Relationship distress
- Unlike other side effects, sexual symptoms do not self-resolve
- Untreated sexual dysfunction tends to worsen over time
- Understudied, especially in diverse, underserved populations where it is likely to be even more underattended to



Common Sexual Problems for Women

Disorders of sexual desire and sexual motivation

- Hypoactive sexual desire
- Reduced sexual motivation
- Decreased body image, loss of sexual self-esteem

Disorders of sexual response

- Arousal
- Female genital arousal disorder/reduced lubrication
- Orgasmic dysfunction
- Chronic dyspareunia



Risk Factors for Sexual Dysfunction

- History of sexual problems, decreased relationship satisfaction before cancer
- Absence of sexual activity returning to “normal” 1 year post treatment
- Poor physical function/functional impairment
- History of depression/anxiety
- Age (young patients have more challenges) and partner status



A Gap in Care

- Majority survivors do not receive support for sexual problems
- Recent study of young breast cancer survivors (diagnosed between ages 20–35 >6mos post-treatment)
 - 60% women met criteria for sexual dysfunction
 - Only 7% of women who would have liked to receive education about cancer-related sexual problems during treatment received any support



Barriers to Intervention

- Culture saturated with sex, but frank conversation about real sex not encouraged
- Clinicians feel unprepared, do not receiving training. Limited time
- Concern about offending patient, or causing discomfort / how to communicate without seeming “overly interested”
- Gender / cultural concerns / disparities
- Clinicians often aren't sure what to say or do if patient endorses a problem (Pandora's box)



Identifying and Assessing Symptoms

Communication about sexual health is hampered by perceived *lack of available brief and effectual patient resources*, including -

- Simple clinical checklists
- Educational materials
- Appropriate referral resources



Questionnaires / Checklists

REVIEW | Current Opinion

How to ask and what to do: a guide for clinical inquiry and intervention regarding female sexual health after cancer

Sharon L. Bober, Jennifer B. Reese, Lisa Barbara,
Andrea Bradford, Kristen M. Carpenter, Shari
Goldfarb, and Jeanne Carter

Sexual Symptom Checklist for Women after Cancer

Please answer the following questions about your overall sexual function:

1. Are you satisfied with your sexual function?

Yes No

2. Do you have any concerns about vaginal health?

Yes No

If not satisfied with sexual function AND/OR concerns about vaginal health, please continue.

3. Do you experience any of the following sexual problems or concerns?

Little or no interest in sex

Decreased sensation (or loss of sensation)

Decreased vaginal lubrication (dryness)

Difficulty reaching orgasm

Pain during sex

Vaginal or vulvar pain or discomfort (not during sex)

Anxiety about having sex

Other Problem or Concern: _____

4. Would you like more information, resources, and/or would you like to speak with

someone about these issues?

Yes No



Or Simple Inquiry...

"Many patients with cancer have questions about sexual function and how treatment impacts sexuality. Do you have anything you would like to ask?"

"Can you tell me about the impact that cancer has had on your sexual function? Is there anything bothering you?"

"Is a physical relationship with your partner an important part of your life, and has your current illness significantly impacted this? Is there anything that you or your partner might want to ask about sexual function?"



Educating Women about Vaginal Health

- Moisture
 - Non-Hormonal Moisturizers
 - Lubricants
 - Vaginal Estrogens and other hormones (selectively in BC)
- Stretch
 - Pelvic Floor Work
 - Dilation Therapy
 - Pelvic PT
- Bloodflow
 - Vibrator Therapy
 - Self-Touch



Pharmacologic and Other Novel Treatments

Treatment for VVA	Specific Therapy/Use
Vaginal estrogen	Local (not systemic) therapy Tablet/ring/cream
Vaginal DHEA	Intravaginal ovules (prasterone)
Lidocaine	For insertional pain. Topical application to vestibule (4% aqueous lidocaine) before sexual activity
Off-label vaginal testosterone	Controversial
Off-label fractional CO ₂ laser	No evidence-base for use after BR CA, recent negative study in gen pop

Treatment for Low Desire	Mechanism of Action
Flibanserin (daily use at bedtime)	5-HT _{1A} serotonin receptor agonist and 5-HT _{2A} receptor antagonist
Bremelanotide (on-demand use)	Melanocortin 1 & 4 receptor agonist

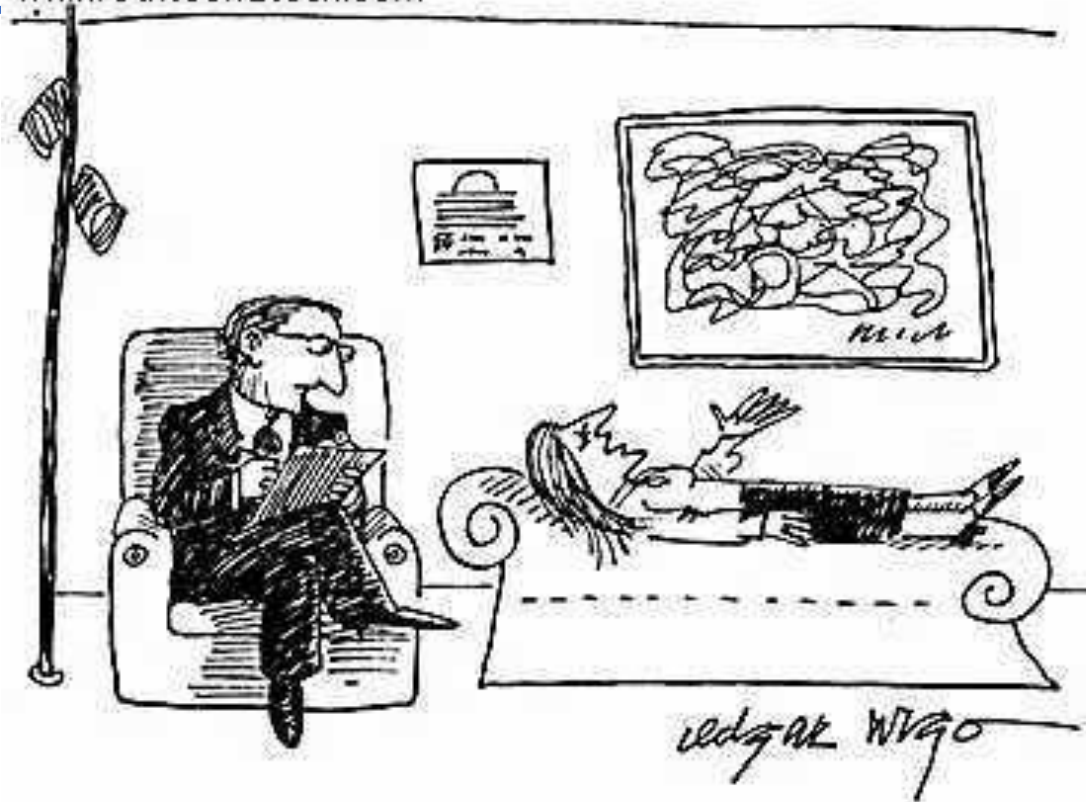


Behavioral Interventions

- Growing evidence-base for behavioral intervention
 - Cognitive-behavioral therapy
 - Mindfulness-based cognitive Therapy / Mindfulness-based sexual Therapy
 - Couples-based intimacy enhancement
 - Psychoeducational interventions
- Recent internet-based RCT: CBT for breast cancer survivors with sexual dysfunction led to improvement in overall sexual functioning, including desire, arousal, and vaginal lubrication.
 - 24 weeks, therapist-guided sessions using telephone-platform
 - Successful but resource and time intensive



© Original Artist
Reproduction rights obtainable from
www.CartoonStock.com



"...WHEN I TOLD HIM I'M NOT ABLE TO REACH AN
ORGASM, HE SAID, 'TRY STANDING ON A CHAIR.'"





Homepage

About Us

Why did this happen?

Coping

Beauty and self-image

Sex and intimacy

Work and school

Having children after
breast cancer

Menopause vs.
menopausal symptoms

Healthy living

Resources

News and education

Research

Breast Cancer in Young Women

A Virtual Forum Series
for Patients and Survivors

October 6 – 29, 2020

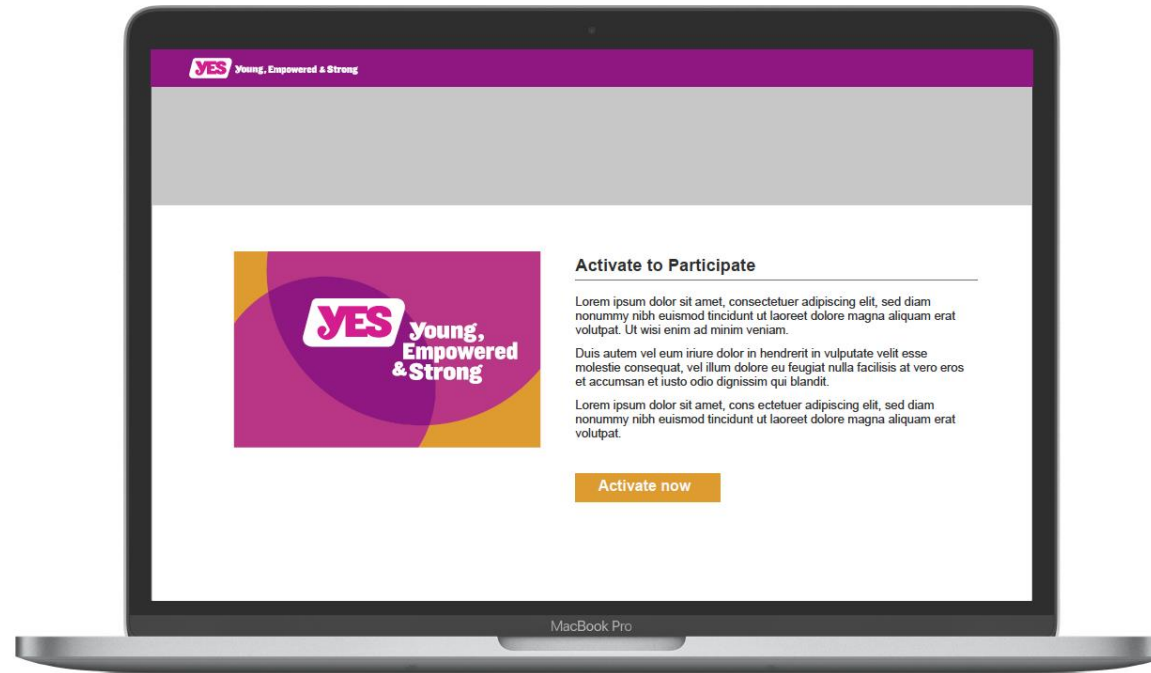
The Young & Strong team is excited to announce the schedule for this year's virtual forum series. Each of the eight events has something unique to offer. Click [here](#) to register.

Schedule of Events

WEEK 1



YES Web-Based Portal



YES Web-Based Portal

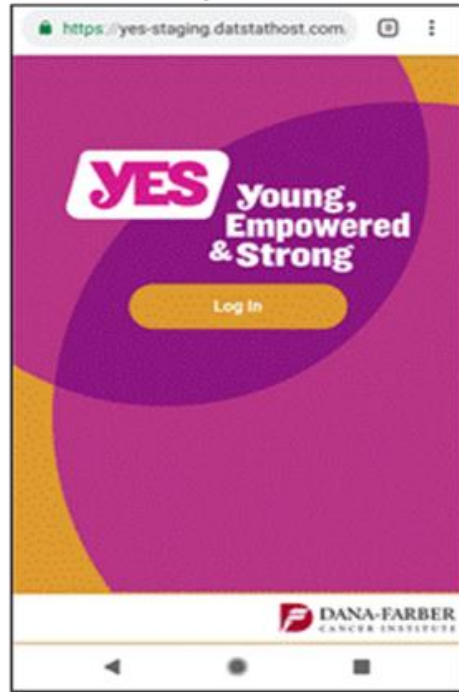
- A multicomponent intervention to engage and activate young women with breast cancer to *self-monitor* and *self-manage* concerns and symptoms by providing tailored information, resources and support.
- YES builds on and extends:
 - Prior web/clinic-based Young and Strong intervention which engaged newly diagnosed patients and their clinicians
 - Serial symptom monitoring into the survivorship period, when chronic symptoms and informational and supportive care needs are prevalent
 - Provision of direct support via chat rooms and expressive writing opportunity
- Model emphasizes self-monitoring and self-management, without heavy clinician involvement and self and peer support



Text Message Prompts

Text Message
Wed, Oct 9, 10:29 AM

You currently have an active survey in your portal that is due. Please click on the link and you will be directed to your portal. <https://yes-staging.datstathost.com/Portal>



Month 1-6 Assessments

AYA concerns

How concerned are you about having your own children in the future?

- Not at all
- A little bit
- Somewhat
- Quite a bit
- Very much

Symptoms

In the last 7 days, how OFTEN did you feel ANXIETY?

- Never
- Rarely
- Occasionally
- Frequently
- Almost constantly

Example of Tailored Content Available Based on Responses to the Assessments

The screenshot shows a mobile app interface with a purple header and a "My Toolbox" section. The toolbox contains several items, with "Pain" and "Anxiety" highlighted. The "Pain" section includes "Understanding pain" and "How can you care for yourself at home?". The "Anxiety" section includes "Understanding anxiety" and "Ways to Ease Your Anxiety".

My Toolbox

- Physical Symptoms Information
 - Mouth or Throat Sores
 - Poor Appetite
 - Nausea/Vomiting
 - Dizziness
 - Pain
 - Musculoskeletal Pain
 - Lymphedema - Arm or Leg Swelling
 - Vaginal Dryness & Pain During Intercourse
 - Sexual Health
- Emotional Symptoms Information
 - Anxiety

Pain

Understanding pain
Pain is the body's way of telling us something is wrong. It tells us to move away from a hot fire or limit activity after an injury.
Patients with cancer may have pain for many reasons:

- The cancer itself. For example, if a tumor grows, it may press on organs or bones, which can lead to pain.
- Cancer treatments, such as chemotherapy, radiation, or surgery.
- Injury such as a strain, sprain or fracture.
- Other conditions not related to cancer, such as arthritis.

It's important to treat pain. If you are in pain, don't put up with it. There are many ways to help reduce pain. Talk with your doctor to learn about physical therapy or medicines that can help you. Ask what other things, like massage or acupuncture, could also help. Remember, being in less pain will help you feel stronger and better.

How can you care for yourself at home?

- Keep track of the pain.
 - Each day, fill in the information below on a piece of paper.
 - The pain is dull, sharp, burning, shooting, or: _____*(Add your own words if these don't)*

YES Pilot Study

- N=30 patients followed for 12 weeks
 - Newly diagnosed/metastatic completed assessments weekly
 - Survivors completed assessments monthly
- 50-80% responded to each 4-week concern and symptom assessment after baseline
- Well received by participants



YES Pilot Study

Top concerns/symptoms triggered by the assessments:

- 1) Sexual health
- 2) Anxiety
- 3) Fatigue
- 4) Stress
- 5) Mindfulness
- 6) Depression
- 7) Mental health services
- 8) Emotional health in survivorship
- 9) Sleep problems
- 10) Vaginal dryness & pain
- 11) Hot flashes & excessive sweating



In Conclusion

- Body image problems and sexual dysfunction are some of the most common, enduring challenges after breast cancer
- Attention to these important survivorship areas, awareness and communication with patients that symptoms can be improved is critical
- Treat or know who you can refer to in your center, system, community to help your patients with these sensitive issues
- Novel interventions more accessible for patients are emerging

