



Cancer Care Ontario

# Interventions to Address Sexual Problems in People with Cancer

**LISA BARBERA**

**PATIENT CENTRED CARE ROUNDS  
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# Acknowledgements and Disclosures

	Affiliation	Disclosure
Lisa Barbera	Associate Prof, DRO, Odette/ UofT	None
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Dean Elterman	Assistant Prof, Dept of Surgery, UHN/UofT	Speaker, advisory board for Lilly, Pfizer Consultant to AMS, Pfizer, Lilly, Astellas
Wendy Wolfman	Director, Menopause Unit, Mt Sinai Hospital	Pfizer funding for research fellow and database support
Ann Katz	Sexuality Counsellor, Cancer Care Manitoba	None
Kathy McPherson	Patient and Family Advisory Council, CCO	None
Andrew Matthew	Psychologist, UHN	None



# Objectives

1. To review the importance of discussing sexual issues with patients
2. To explain the content of the new PEBC guideline regarding sexual function in cancer patients

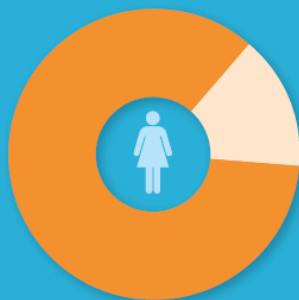


# Background

## Sexual dysfunction in cancer patients is a significant problem.

### The Burden

Sexual dysfunction in cancer patients is a significant problem.



**Up to 85%**  
Of women with cancer (breast, cervical and colorectal) may experience difficulties with sexual function

**Up to 95%**  
Of men with cancer (prostate, testicular, colorectal and bladder) may experience sexual difficulties



### Sexual Health Related Distress



**60%**

- Up to 60% of men with cancer report distress due to sexual dysfunction

**50%**

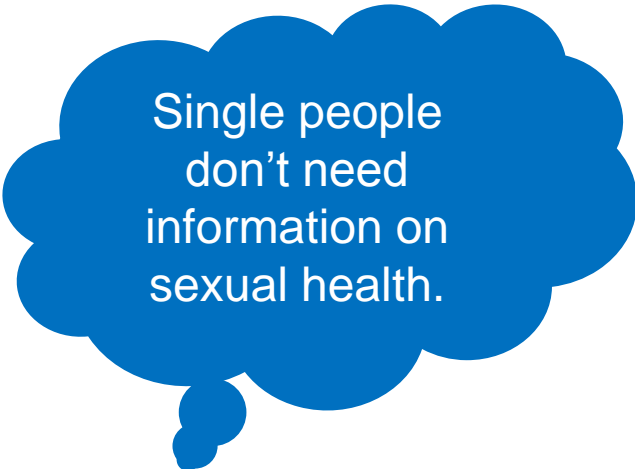


- 50% of women are distressed by changes in sexual functioning and body image after a gynecologic cancer diagnosis
- More than 50% of women with breast cancer have distress due to sexual dysfunction




- The majority of partners of prostate cancer patients also report significant distress


# Stereotypes and Misconceptions




Single people  
don't need  
information on  
sexual health.



Older individuals  
are not interested  
in having sex.



People who are  
not sexually active  
don't need this  
information.



Cancer patients  
care about the  
effectiveness of  
cancer treatment,  
not quality of life.

# Barriers to Conversation



**Environment** – Want to converse in a private area



**Time** – There's not enough time for conversations



**Training** – Sexual health regarding cancer patients is not included in many training programs



**Resources** – Lack of awareness about available resources



**Comfort Level** – Personal areas of discomfort

# Patient Experience

*“It wouldn’t have mattered when I got the information because I would have had the treatment anyhow...but it would have been good to be more prepared about what was going to happen so that it wasn’t a surprise...I asked myself, ‘**This** as well, what next? What else haven’t they told me about?’”*

Prostate cancer patient at a follow-up clinic appointment commenting on his experiences with erectile dysfunction after surgery.



Cancer • Cancer Education

# Let's talk about sex — a cancer patient's perspective

September 21, 2016 • by Aviva Rubin



Written by Aviva Rubin

## Latest tweets

### Tweets by @Sunnybrook



Sunnybrook Hospital

@Sunnybrook

Today is World Contraception Day. What you need to know about emergency contraception:

[health.sunnybrook.ca/women/emergenc](http://health.sunnybrook.ca/women/emergenc)... #WCD2016



Emergency contraception: w...

Oral emergency contraception, c...  
[health.sunnybrook.ca](http://health.sunnybrook.ca)



Sunnybrook Hospital

@Sunnybrook

I'm cold, tired and depressed — is there something wrong with my thyroid?

[health.sunnybrook.ca/wellness/thyro...](http://health.sunnybrook.ca/wellness/thyro...)

Embed

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# Aviva's advice for clinicians and staff

Cancer is a weird world. Let patients know from the outset that no question or observation about anything they're experiencing is too personal or awkward to be raised. There may not be an answer for everything, but acknowledging the experiences and letting people know they are not alone really helps.

Normalize the discussion of sex, sexual dysfunction, intimate relationships and cancer.

Raise the issue of sexual health regularly and as a matter of course. Don't make the patient or their loved one bring it up first.

Assume that sex and sexuality is important to all patients. Let *them* tell you they don't need to discuss it.

Be mindful that your patients may identify as lesbian, gay, bisexual or transgender. That can add an additional layer to an already difficult discussion. Don't make assumptions.

Know where to point your patients and their caregivers for more information.

*"I hope that by providing healthcare providers with the Interventions to Address Sexual Problems in People with Cancer clinical guideline, they will not only be better able to support the physical and emotional impact that cancer has on a patient's sexual health and well-being, but it will also begin to normalize the conversation around sexual health. **I am confident that the guideline will help improve the quality of life for patients and families dealing with sexual health in the future.**"*

– Kathy M., Patient Family Advisor & Guideline Development Working Group member



## **Guideline 19-6**

**A Quality Initiative of the  
Program in Evidence-Based Care (PEBC), Cancer Care Ontario (CCO)**

# **Interventions to Address Sexual Problems in People with Cancer**

*L. Barbera, C. Zwaal, D. Elterman, K. McPherson, W. Wolfman, A. Katz, A. Matthew and the  
Interventions to Address Sexual Problems in People with Cancer Expert Panel*

**Report Date: April 28, 2016**

**Google: “PEBC sexual function”**

## Objective

- To examine effective strategies/interventions to manage sexual function side effects as a result of cancer diagnosis and/or treatment

## Target Audience

- Health practitioners such as oncologists, radiation therapists, urologists, gynecologists, primary care providers, surgeons, nurses, physiotherapists, social workers, counsellors and psychiatrists

# Methods

- Searched existing guidelines, systematic reviews and relevant primary literature from 2003-2015
- Men and women evaluated separately
- No restriction on cancer type or study design
- Authors defined a list of common conditions *a priori* to focus and organize work
- Only included studies that evaluated the impact of an intervention on a sexual health outcome
- Grouped interventions as pharmacologic, psychosocial counselling or devices



Women	Men
Sexual response <ul style="list-style-type: none"> <li>• Decreased desire</li> <li>• Decreased arousal</li> <li>• Orgasm (alternate sensation and anorgasmia)</li> </ul>	Sexual response <ul style="list-style-type: none"> <li>• Decreased desire</li> <li>• Erectile dysfunction</li> <li>• Orgasm (alternate sensation and anorgasmia)</li> <li>• Absence of ejaculate</li> </ul>
Body image <ul style="list-style-type: none"> <li>• Urinary/fecal incontinence</li> <li>• Ostomies</li> <li>• Alopecia (loss of body hair)</li> <li>• Mastectomy and lumpectomy</li> </ul>	Body Image and Penile Changes <ul style="list-style-type: none"> <li>• Urinary/fecal incontinence</li> <li>• Ostomies</li> <li>• Alopecia (loss of body hair)</li> <li>• Penile/testicular changes in size and shape</li> </ul>
Intimacy/relationships	Intimacy /relationships
Overall sexual function and satisfaction	Overall sexual function and satisfaction
Vasomotor symptoms	Vasomotor symptoms
Genital symptoms <ul style="list-style-type: none"> <li>• Dryness</li> <li>• Vaginal stenosis</li> <li>• Pelvic pain</li> <li>• Graft versus host disease</li> </ul>	
Other <ul style="list-style-type: none"> <li>• Fatigue</li> <li>• Dry mouth</li> </ul>	Other <ul style="list-style-type: none"> <li>• Fatigue</li> <li>• Dry mouth</li> </ul>

# Evaluation of the evidence

- Guidelines evaluated with AGREE criteria
- Systematic reviews evaluated with AMSTAR criteria
- Randomized controlled trials evaluated with Cochrane Risk of Bias Tool
- Non-randomized trials evaluated based on elements identified as important for quality in non-randomized studies
- All primary evidence evaluated as a whole using GRADE methodology



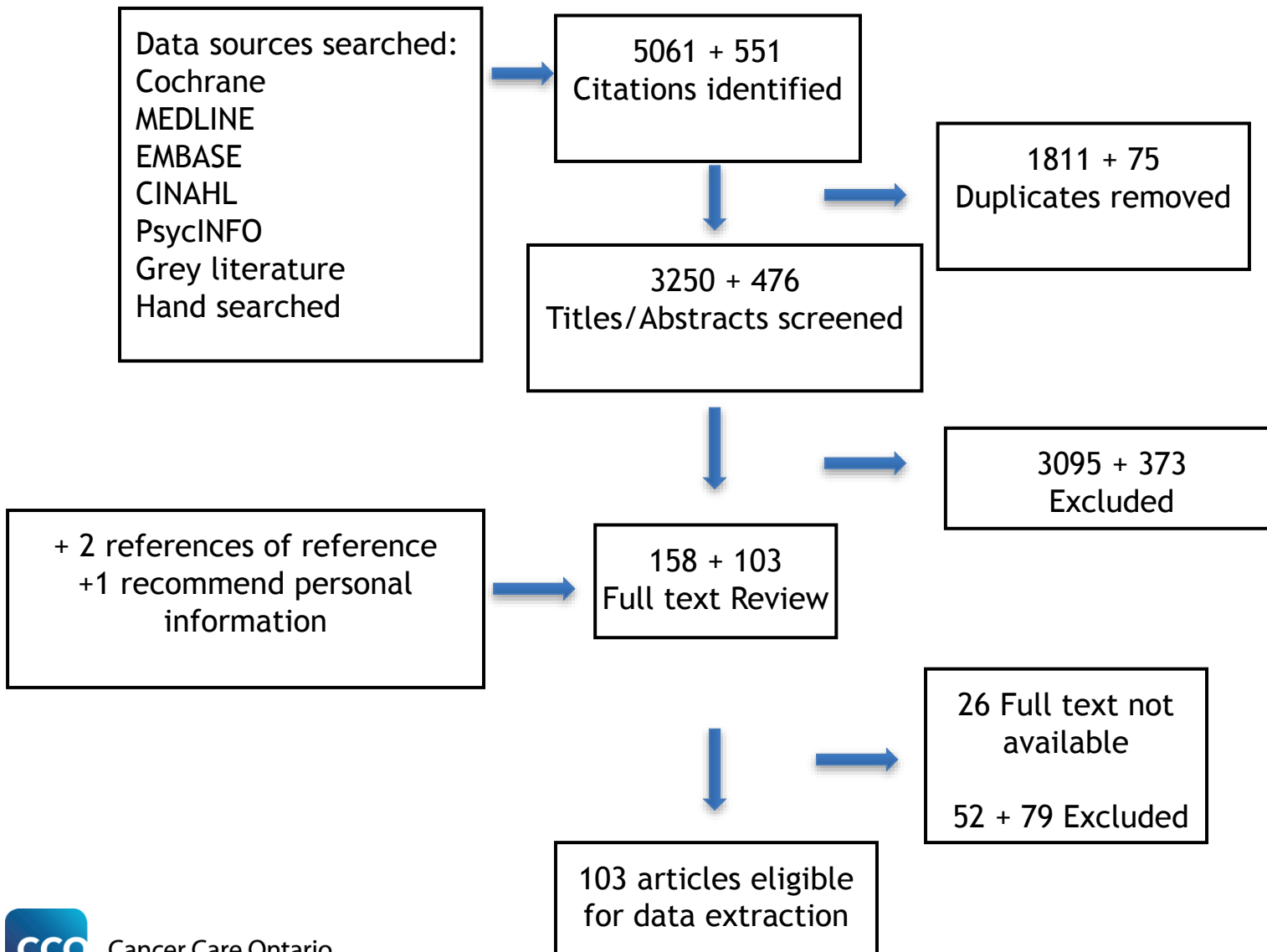


# Data extraction

- Data extraction performed by one authors (CZ)
- Reviewed by a second independent individual using a data audit procedure
- Disagreements resolved by consensus
- Meta-analysis not planned



# PRISMA Flow Diagram



- 4 guidelines
- 13 systematic reviews
- 103 primary literature references
- Expert opinion



## For all people with cancer

### Recommendation 1

It is recommended that there be a discussion with the patient, initiated by a member of the healthcare team, regarding sexual health and dysfunction resulting from the cancer or its treatment. Ideally, the conversation would include the patient's partner, if partnered. This issue should be raised at the time of diagnosis and continue to be re-assessed periodically throughout follow-up.

The Expert Panel believe that this is a vital recommendation. The recommendations that follow cannot be used unless someone has taken the initiative to ask.

It is recommended that there be access to resources or referral information for the patient (and partner).



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# Summary of women's recommendations

	Psychosocial Counselling	Pharmacologic	Devices
Sexual Response	+		
Body Image	+		
Intimacy/Relationships	+		
Overall function/satisfaction	+		
Vasomotor symptoms	+	+	
Genital symptoms	+	+	+



# Summary of men's recommendations

	Psychosocial Counselling	Pharmacologic	Devices
Sexual Response	+	+	+
Genital changes		+	+
Intimacy/Relationships	(+)		
Overall function/satisfaction	+	+	
Vasomotor symptoms		+	



# Other interventions mentioned in the guideline

	Women	Men
Sexual Response	masturbation	masturbation
Body Image		
Intimacy/Relationships		
Overall function/satisfaction	exercise	
Vasomotor symptoms		accupuncture
Genital symptoms	exercise	

# Comments on psychosocial counselling

- Counselling and education have big role to play for most outcomes, but questions remain:
  - what is the ideal intervention?
  - what are most important components?
  - Should target be couples or group or individual?
  - person/telephone/web based?
  - Minimum duration?
  - Recommendations also consider risk of harm
- Pre-existing difficulties will complicate assessment and management



# Limitations



## Populations

- For women mostly breast, some gynaecological
- For men mostly prostate, some colorectal
- Nothing e.g. for head and neck
- LGBTQ



## Methods

- Low response rates
- Lack of power calculations
- Lack of randomization
- Selective reporting
- Variety of measures, even within domain



## Further work

- Role of testosterone for low libido
- Pro-erectile therapies for penile rehab
- Role of hormone therapy for younger women with premature ovarian failure

# Plans to support guideline roll out

## PSO program has a specific plan

- Increasing guideline awareness
- Normalization of sexual health and facilitation of guideline uptake
- Educational opportunities and promotional materials for providers and patients

## Resource Hub

- Resources for patients and providers
- Scripts for sample language, how to start the conversation
- Where to find further opportunities for education/training



# Additional Resources

Canadian Cancer Society's "[Sexuality and Cancer](#)" page

Canadian Cancer Society's "[Sexuality and Cancer](#)" publication

Prostate Cancer Canada's "[Sexual Side Effects](#)" page with webinars

Scientific Network on Female Sexual Health and Cancer's "[Resources for Cancer Survivors](#)" page

CCO Sexual Health in Cancer Resource Hub (under development)



