

#### What about me? Understanding the unmet sexual and support needs of female partners of men with prostate cancer.



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#### THE JOURNAL OF

**ORIGINAL RESEARCH & REVIEWS** 

#### ONCOLOGY

#### Guidelines for Sexual Health Care for Prostate Cancer Patients: Recommendations of an International Panel

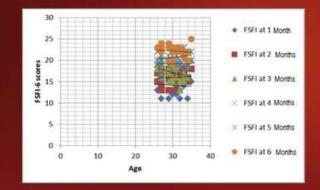
Check for updates

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J Sex Med, 2022 Nov;19(11):1655-1669

### THE JOURNAL OF SEXUAL MEDICINE

Volume 19, Number 11, November 2022 www.jsm.jsexmed.org



An Official Journal of The International Society for Sexual Medicine

Asia Pacific Society for Sexual Medicine (APSSM); European Society for Sexual Medicine (ESSM); Latin American Society for Sexual Medicine (SLAMS); Middle East Society for Sexual Medicine (MESSM); Sexual Medicine Society of North America (SMSNA); South Asian Society for Sexual Medicine (SASSM); International Society for the Study of Women's Sexual Health (ISSWSH)







#### Guidelines for Sexual Health Care for Prostate Cancer Patients: Recommendations of an International Panel

### Statement 1

A clinician-initiated discussion should be conducted with the patient and the partner (if partnered and culturally appropriate) about realistic expectations of the impact of prostate cancer therapy on the patient's sexual function, the partner's sexual experience, and the couples' sexual relationship. The clinician should promote openness and inclusivity, consider cultural context, and tailor counseling to the specific needs of patients who are heterosexual, gay, bisexual, identify as men who have sex with men, transgender women and gender non-conforming individuals. (Strong Recommendation; Evidence Strength Grade C).



Wittmann D, Mehta A, McCaughan E, Faraday M, Duby A, Matthew A, Incrocci L, Burnett A, Nelson CJ, Elliott S, Koontz BF, Bober SL, McLeod D, Capogrosso P, Yap T, Higano C, Loeb S, Capellari E, Glodé M, Goltz H, Howell D, Kirby M, Bennett N, Trost L, Odiyo Ouma P, Wang R, Salter C, Skoura TA, McPhail J, McPhail S, Brandon J, Northouse LL, Paich K, Pollack CE, Shifferd J, Erickson K, Mulhall JP. Guidelines for Sexual Health Care for Prosted Cancer Patients: Recommendations of an International Panel. J Sex Med 2022;19:1655–1669



# These are the first sexual health guidelines that have been developed for the care of cancer patients.



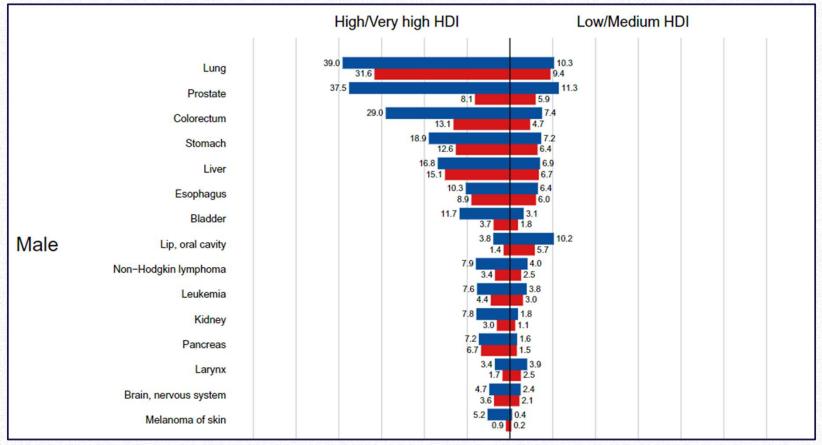


## Background



## **Global Cancer Mortality**





Sung et al., CA CANCER J CLIN 2020



Complete our session survey to enter a raffle for a FREE one-year ISSM membership!







### Instructions



- Scan the QR code with your device or go to <u>www.issm.info/movember</u>
- This poll gathers insights to improve sexual health guidelines and resources in prostate cancer care through the ISSM and Movember partnership.





### Sex after Prostate Cancer Therapy The Conversation



#### John P. Mulhall MD MSc FECSM FACS FRCSI

Director Sexual & Reproductive Medicine Program Urology Service Memorial Sloan Kettering Cancer Center

## Disclosures

#### Grants

- NIH (Chris J. Nelson PhD)
- DOD (Stacy Loeb MD)
- Sexual Medicine Society of North America (JPM Mentor)
- Urology Care Foundation (JPM Mentor)

#### Academic Leadership Positions

• Secretary-General, ISSM

#### Consultancies

• Ro, Firmtech









## Pelvic Urological & Gynecological Cancers are common

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## Sex is a multi-faceted activity and to claim otherwise, reeks of penocentricity

### The Sins in Sexual Medicine



- Ageism
- Projection
- Judgement
- Intolerance
- Apathy
- Oncocentricity (parentalism)?



### Barriers to Discussing ED

#### Patient

Embarrassment Shame Ignorance about normatives Cultural beliefs Religious beliefs Discomfort

#### Physician

Discomfort Lack of Knowledge Personal bias Time



Humphery S, Nazareth I. Fam Pract. 2001;18:516-518.





### **Sexual Dysfunctions**

- Erectile dysfunction (3-90%)
- Anejaculation (100%)
- Low sex drive (50%)
- Changes in orgasm nature/intensity (90%+/50%)
- Dysorgasmia (painful orgasm, 15%)
- Climacturia (60%/20%)
- Arousal incontinence (40%)
- Penile volume alterations (70%)
- Peyronie's disease (15%)





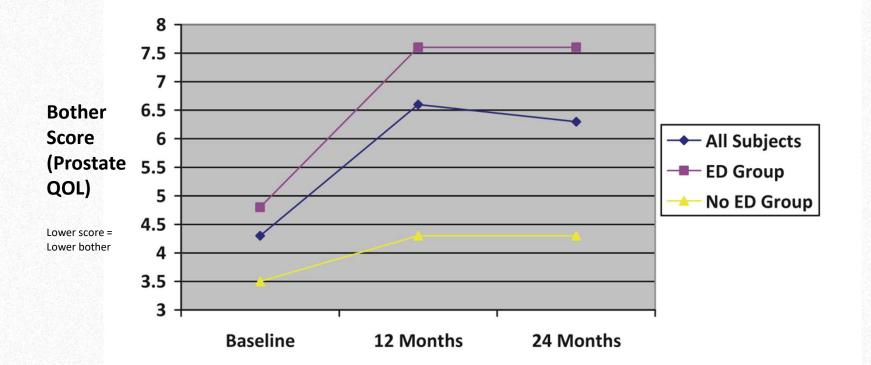
#### Sexual Dysfunctions Google Search October 2024

- Erectile dysfunction (523k)
- Anejaculation (17k)
- Dysorgasmia (3k)
- Climacturia (9k)
- Arousal incontinence (280k)
- Changes in orgasm (1.1M)
- Low sex drive (3.1M)
- Penile volume alterations (4.8M)
- Peyronie's disease (171k)





### EF & Sexual Bother Post-RP



Nelson CJ et al. J Sex Med 2010;7:129–135.

MOVEMBER

### Statement 1



A clinician-initiated discussion should be conducted with the <u>patient and the partner</u> (if partnered and culturally appropriate), to educate them about realistic expectations of the impact of prostate cancer therapy on the patient's sexual function, <u>the partner's sexual experience</u>, and the couples' sexual relationship. The clinician should promote openness and inclusivity, consider cultural context, and tailor counseling to the specific needs of patients who are heterosexual, gay, bisexual, or identify as men who have sex with men, and of transgender women and gender non-conforming patients. Strong Recommendation; Evidence Strength Grade C



#### Clinicians' Perceptions of Barriers to Sexual Health Discussions

Table 3. Provider-reported barriers to sexual health counseling of female patients undergoing radical cystectomy and their partners

Barrier, n (%)	N = 140
Older patient age	71 (50.7)
Inadequate time to discuss	66 (47.1)
Uncertain about patients' baseline sexual function	52 (37.1)
Concerned patient would feel uncomfortable	37 (26.4)
Lack of knowledge about female sexual function	28 (20.0)
Uncomfortable counseling patient/partner	15 (10.7)
Outside the scope of urologic oncology practice	7 (5.0)





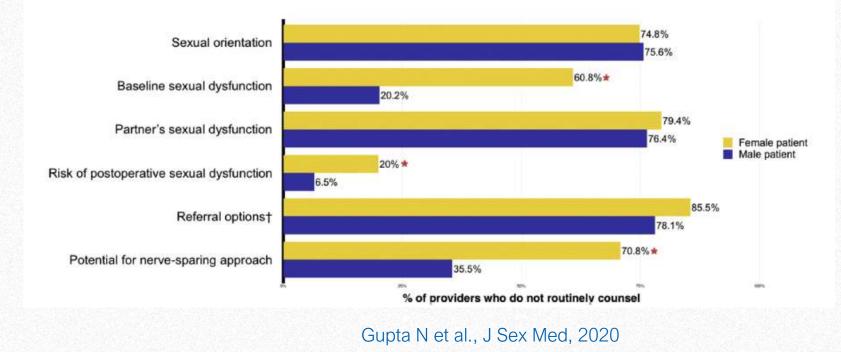




### Patient Counseling (Cystectomy)

#### 140 urologic oncologists were surveyed

Percent of providers who do not routinely provide preoperative sexual health counseling to sexually active male and female radical cystectomy patients, by topic





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VOLUME 22 · NUMBER 4 · FEBRUARY 15 2004

JOURNAL OF CLINICAL ONCOLOGY

#### ORIGINAL REPORT

#### Measuring Quality of Life in Routine Oncology Practice Improves Communication and Patient Well-Being: A Randomized Controlled Trial

Galina Velikova, Laura Booth, Adam B. Smith, Paul M. Brown, Pamela Lynch, Julia M. Brown, and Peter J. Selby

A B S T R A C T

#### Purpose

To examine the effects on process of care and patient well-being, of the regular collection and use of health-related quality-of-life (HRQL) data in oncology practice.

Submitted June 18, 2003; accepted December 5, 2003.

United Kingdom.

From the Cancer Research UK Clinical

pital: and Northern and Yorkshire Clini-

cal Trials and Research Unit, Leeds,

Centre-Leeds, Cancer Medicine Research Unit, St James's University Hos-

#### **Patients and Methods**

In a prospective study with repeated measures involving 28 oncologists, 286 cancer patients were



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### Statement 3



Patients and partners should be advised that psychological distress, including grief and mourning about sexual losses, resulting from the sexual side-effects of prostate cancer therapies, can be experienced by patients after prostate cancer therapy and by their partners and that this distress can be mitigated with appropriate biopsychosocial rehabilitation strategies.

Strong Recommendation; Evidence Strength Grade C



### The Conversation

- Engendering the appropriate environment
- PLISSIT or other models?
- Integrating open-ended questions?
- Define goals
- Appreciate dyadic elements
- Understand the multi-domained structure of sexual function
- Define source and magnitude of sexual dissatisfaction







## <u>Sexual Concerns of the Partner</u> of the Patient with Prostate cancer - Female

### Domains

- Distress (6)
- Loss of connection (4)
- Active communication (2)
- Discomfort with communication (1)
- Frustration with sexual counseling (3)
- Expansion of sexual repertoire (2)
- Non-penetrative relation (1)





### **Final Inventory**

- 1. I am experiencing distress related to the sexual changes from the prostate cancer diagnosis and/or treatment. (1)
- 2. I am satisfied with the current state of my sex life with my partner since the prostate cancer diagnosis and/or treatment. (8R)
- 3. My sexual needs are currently being met. (9R)
- 4. My sex life is worse since the prostate cancer diagnosis and/or treatment. (10)
- 5. I feel a loss of intimacy from my partner since the prostate cancer diagnosis and/or treatment. (12)
- 6. My partner avoids intimate situations since the prostate cancer diagnosis and/or treatment. (13)
- 7. I feel less physically attracted to my partner since the prostate cancer diagnosis and/or treatment. (6)
- 8. I have felt more isolated from my partner since he was diagnosed with prostate cancer. (11)
- 9. I feel invisible to my partner since he was diagnosed with prostate cancer. (14)



### **Final Inventory**

10. My partner and I are less close since the prostate cancer was diagnosed. (15)

- 11. I tell my partner how I feel about our current sex life. (23R)
- 12. My partner tells me how he feels about our current sex life. (24R)
- 13. I am uncomfortable talking with my partner about our sexual problems. (25)
- 14. I received a satisfactory explanation of the sexual side effects of prostate cancer procedure(s) and/or treatment(s). (18R)
- 15. I am frustrated/angry about the lack of information we received about sexual health.(19)
- 16. I felt prepared for the sexual side effects. (20R)
- 17. I am comfortable trying new ways to achieve sexual satisfaction outside of intercourse. (3R)
- 18. We have become more flexible in how we initiate physical intimacy (eg, who initiates, type of contact) since the prostate cancer diagnosis and/or treatment. (4R)
- 19. I am satisfied with hugging, kissing and other intimate activities, rather than sexual intercourse. (2R)







### **Take Home Messages**

- Partner inclusion is critical to outcomes optimization
- Sex after PC therapy will be different for patient & partner
- A need for SCIPPP-F exists
- PC treatment has an impact on female partner sexual health
- SCIPPP-F can be used before and after PC treatment
- Questionnaire is reliable and valid (USA population)
- ASK THE QUESTION!



## Let us not focus solely on adding years to life, but also pay attention to adding *life* to years



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# THANK YOU



## The impact of prostate cancer sexual side - effects on the female partner



Annamaria Giraldi, MD, PhD

Professor of Clinical Sexology, FECSM & Sexual Counselor

Mental Health Center Copenhagen, Copenhagen University Hospital and Dep. Of Clinical Medicine, University of Copenhagen, Denmark

## Disclosures

- Eli Lilly lecturer, consultant, lecturer,
- Pfizer/ Viatris advisory board
- Sandoz advisory board
- Futura Medical/Eroxon advisory board, lecturer
- Astellas lecturer
- Lundbeck lecturer
- Novo Nordic stockholder, lecturer
- FREYA advisory board, lecturer





### Statement 19



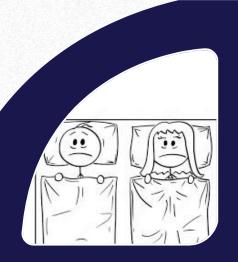
Patients and partners should be counseled that an assessment of the partner's sexual function can help plan treatment designed to support couples' recovery of sexual intimacy.

**Clinical Principle** 





## A couple experience

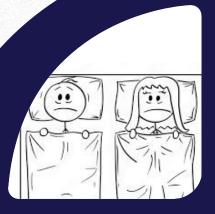


Sexual Dysfunction in Female Partners of Men Who Have Undergone Radical Prostatectomy Correlates with Sexual Dysfunction of the Male Partner

Alan Shindel, MD,\* Sejal Quayle, MD, MPH,\* Yan Yan, PhD,\* Adnan Husain, MS,<sup>†</sup> and Cathy Naughton, MD\*

- 90 couples
- Men with PCA and their female partner
- International Index of Erectile Function (IIEF)
- Female Sexual Function Index (FSFI)





#### Table 4 Correlation between domains of the IIEF and FSFI by Pearson correlation coefficient

Domain	IIEF—Erectile Function	IIEF—Orgasmic Function	IIEF—Sexual Desire	IIEF—Intercourse Satisfaction	IIEF—Overall Satisfaction	IIEF—Overall Sexual Function
FSFI—Desire	0.13	0.22*	0.21*	0.24*	0.21*	0.08
FSFI—Arousal FSFI—Lubrication	0.47* 0.59*	<i>0.38*</i> 0.57*	0.31* 0.37*	0.41* 0.55*	0.40* 0.50*	0.21* 0.35*
FSFI—Orgasm	0.52*	0.41*	0.35*	0.45*	0.45*	0.22*
FSFI—Satisfaction	0.53*	0.37*	0.35*	0.44*	0.55*	0.29*
FSFI—Pain	0.66*	0.45*	0.38*	0.67*	0.45*	0.37*
FSFI—Total	0.63*	0.51*	0.42*	0.59*	0.55*	0.33*

\*P < 0.05.

Weak correlations are italicized; strong correlations are bold.





# What happens with the partner in the couple?



### The Experiences and Unmet Supportive Care Needs of Partners of Men Diagnosed With Prostate Cancer Cara Roberts, BSc, OT

A Meta-aggregation Systematic Review Cancer Nursing<sup>®</sup>, Vol. 00, No. 00, 2022 = 1 Cara Roberts, BSc, OT Kellie Toohey, PhD, MCEP, BSc, PG Cert Research, PG Cert Tertiary Ed, AEP Catherine Paterson, PhD, BA, MSc, PgCert LTA, FHEA, RAN

- 20 studies
- 6 countries (UK, USA, Denmark, Norway, Australia & Canada)
- 380 partners included, most were female
- Age from 32 88 years



Following a prostate cancer diagnosis, the partner is seen as a crucial companion in the cancer care continuum, with the partner's support playing an instrumental role in the man's ability to successfully transition from the acute phase of the disease to long-term survivorship



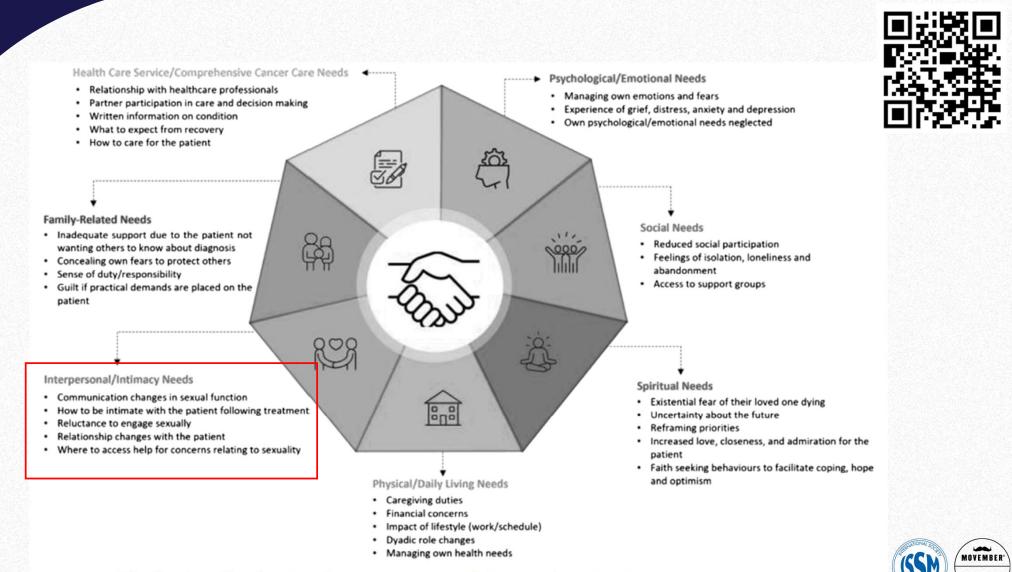


Figure 2 ■ Classification of the domains of supportive care needs (partners/caregivers).

#### Interpersonal/Intimacy Needs

- Communication changes in sexual function
- How to be intimate with the patient following treatment
- Reluctance to engage sexually
- Relationship changes with the patient
- Where to access help for concerns relating to sexuality



# Interpersonal/ intimacy needs



- Shift of focus to affirming couple bond to maintain intimacy
- Lack of intercourse as an indication of attraction of attraction intercourse as an indication of attraction intercourse as an indication of attraction intercourse as an indication of attraction of attraction intercourse as an indication of attraction of attracti
- Differences in communication 
  reduced level of physical and emotional intimacy 
  doubt about the relationship



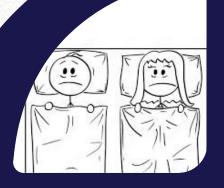
# Interpersonal/ intimacy needs

- Protects the man's sense of masculinity
- Grief
- Take the lead in sexual initiative
- Mindful it was a gradual process to resume sexual activity





#### J Sex Med 2022;



ONCOLOGY

#### Unmet Sexual Health Needs of Patients and Female Partners Following Diagnosis and Treatment for Prostate Cancer

Randall Li, MD,<sup>a</sup> Daniela Wittmann, PhD, MSW,<sup>b</sup> Christian J. Nelson, PhD,<sup>c</sup> Carolyn A. Salter, MD,<sup>d</sup> John P. Mulhall, MD,<sup>e</sup> Nataliya Byrne, BA,<sup>a</sup> Tatiana Sanchez Nolasco, MPH,<sup>a</sup> Marina Ness, MPH,<sup>f</sup> Natasha Gupta, MD,<sup>a</sup> Caroline Cassidy, BA,<sup>c</sup> Theodore Crisostomo-Wynne, MD,<sup>d</sup> and Stacy Loeb, MD, MSc, PhD<sup>a</sup>

- Qualitative study of posts to the: Inspire Us TOO Prostate Cancer Online Support and Discussion Community
- 661 posts from women analyzed 66 (10%)
- 66 posts from male patients



	Patient (%, n = 66)	Partner (%, n = 66)	Nagative Emotions		
Prostate Cancer Treatment of the			Negative Emotions Frustration	23%	32%
Associated Patient			Loss of familiar sexual interaction	14%	21%
Surgery	39%	39%	Fear	6%	9%
Radiation therapy	3%	18%	Anger	6%	12%
Hormonal therapy	3%	30%	Interpersonal Relationship Problems	070	12-70
Sexual Dysfunction			Communication difficulties	2%	18%
Erectile dysfunction	85%	83%	Feeling of being pushed away	3%	11%
Penile shortening	8%	0%	Relationship conflict	2%	14%
Penile curvature	2%	2%	Isolation	2%	8%
Pain with erection	2%	2%	Concern that sex life is over	0%	9%
Problems with orgasm or	12%	11%	Sexual Health Treatment	0.0	510
ejaculation			Oral medications (ie, PDE-5	20%	35%
Loss of libido	5%	17%	inhibitors)	2010	e de la companya de l
Positive Emotions		$\frown$	Vacuum erection device (VED)	24%	12%
Hope	15%	29%	Intracavernosal injections (ie,	14%	25%
Gratitude	14%	26%	Bimix, Trimix)		
Satisfaction	27%	18%	Penile prosthesis (IPP)	11%	5%
Relief	11%	14%	Psychosocial treatment	0%	5%

### Partner Concerns

- Expanding the Sexual Repertoire
- Needs for intimacy and sexuality overlooked
- Survival > Sex
- Relationship concerns
- Importance of access to erectile aids





# Couple's Concerns



- Desire to share experiences with sexual recovery and sexual aids
- Coming to terms with changes in sexual function
- Frustration with insufficient sexual counseling from clinicians
- Lack of inclusion of the partner







### **Take Home Messages**

- Prostate Cancer is a "couple's disease"
- The partners and the couple's sexual health is affected negatively
- The partner's sexual health suffers, as do other aspects of their life
- There is a wish for more counseling and access to help from the clinicians





# THANK YOU

Annamaria.giraldi@regionh.dk



### How Couples Adjust Psychologically and Sexually after Prostate Cancer Treatment



Daniela Wittmann, PhD, LMSW Associate Professor of Urology Emerita AASECT Certified Sex Therapist and Therapy Supervisor University of Michigan, Ann Arbor, MI, USA

# Disclosure









### Let's Agree on a Couple Based Approach to Sexual Recovery after Prostate Cancer

Sexual Medicine Reviews, 2024, 12, 35–47 https://doi.org/10.1093/sxmrev/qead044 Advance access publication date 31 October 2023 Review



# Mapping the contributions of dyadic approaches to couples' psychosocial adaptation to prostate cancer: a scoping review

Rita F. Castro, MSc<sup>1,\*</sup>, Silvana Araújo, BSc<sup>2</sup>, Ana Marques, MSc<sup>1</sup>, Diana Ferreira, MSc<sup>1</sup>, Hélia Rocha, MSc<sup>1</sup>, Sandra Aguiar, MSc<sup>1</sup>, Sonia Pieramico, MSc<sup>1</sup>, Ana Quinta-Gomes, PhD<sup>1</sup>, Inês M. Tavares, PhD<sup>3</sup>, Pedro J. Nobre, PhD<sup>1</sup>, Joana Carvalho, PhD<sup>4</sup>

- 25 studies reviewed
- Partners should be included because they are affected by the patient's experience of cancer (*Northouse, Kayser*)



Laurel Northouse PhD



Karen Kayser PhD



Sexual Medicine Reviews, 2024, 12, 35–47 https://doi.org/10.1093/sxmrev/qead044 Advance access publication date 31 October 2023 Review



#### Mapping the contributions of dyadic approaches to couples' psychosocial adaptation to prostate cancer: a scoping review

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- Sexual function/dysfunction of patients and partners is related (too many studies to mention)
- Patients' and partners' coping styles affect each other (Manne, Bodenmann, Fagundes)





Sharon Manne PhD

Guy Bodenmann PhD



Chris Fagundes PhD





### Promoting Realistic Expectations and Addressing Loss and Grief is Important for both Patients and Partners



#### Education

#### Preparing Patients and Partners for Recovery From the Side Effects of Prostate Cancer Surgery: A Group Approach

Kellie Paich, Rodney Dunn, Ted Skolarus, James Montie, Brent Hollenbeck, Ganesh Palapattu, David Wood Jr., Staci Mitchell, Victor Hola, Kim Erickson, Jennifer Shifferd, and Daniela Wittmann

#### Patient Preoperative Expectations of Urinary, Bowel, Hormonal and Sexual Functioning Do Not Match Actual Outcomes 1 Year After Radical Prostatectomy

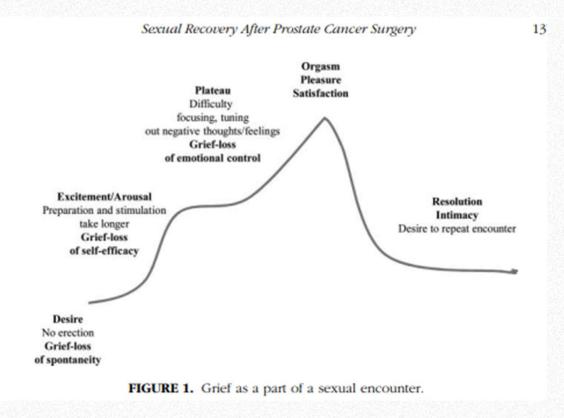
Daniela Wittmann,\* Chang He, Michael Coelho, Brent Hollenbeck, James E. Montie and David P. Wood, Jr.†

- 32% patients thought that erections would be worse after surgery
- As many as 11% patients thought that erections would be better after surgery

- 73% patients thought that erections would be worse after surgery
- 65% partners thought that erections would be worse after surgery
- 84% patients thought the ability to be sexually active after prostatectomy would be different
- 78% partners thought that the ability to be sexually active after prostate cancer would be different
- 4% patients thought erections would be better after surgery

### Grief and Mourning Occurs During Sexual Activity





MOVEMBER"

Wittmann et al., J Mar and Sex Ther, 2011



## Patients and Partners Have Shared and Unique Grief Foci

Men and partners share grief about

- The loss of spontaneity
- Familiar sexual interactions



#### Men singularly grieve

- Loss/change of body image see erections daily throughout their lives
- Threat to masculinity
- Confidence about satisfying the partner
- The pleasure of ejaculation



Partners singularly grieve

- Penetration
- The man's confidence during sex, sometimes his leadership
- The way in which the man's erection is interpreted as a sign that the patient finds the partner attractive







### What Helps Couples Recover?

Factors Contributing to a More or Less Successful Couples' Sexual Recovery (from a study of 20 couples with prostate cancer)

 Post-surge sexual action
 positive inte

"I wish I could be back to being unselfconscious!"

Patient and Partner post-prostatectomy

(not return of erectile function)

 Post-surgery selfinfrequent sexual activity, sexuality, partner's low or Josses, no or Joors, inflexible Jost sex *regardless of menopause* 



poing

ier's

Wittmann et al., J Sex Med, 2015

#### Prostate cancer and the impact on couples: a qualitative metasynthesis

Nicole Collaço<sup>1</sup> · Carol Rivas<sup>2</sup> · Lauren Matheson<sup>1</sup> · Johana Nayoan<sup>2</sup> · Richard Wagland<sup>2</sup> · Obrey Alexis<sup>1</sup> · Anna Gavin<sup>3</sup> · Adam Glaser<sup>4</sup> · Eila Watson<sup>1</sup> Supp Care Ca, 2018

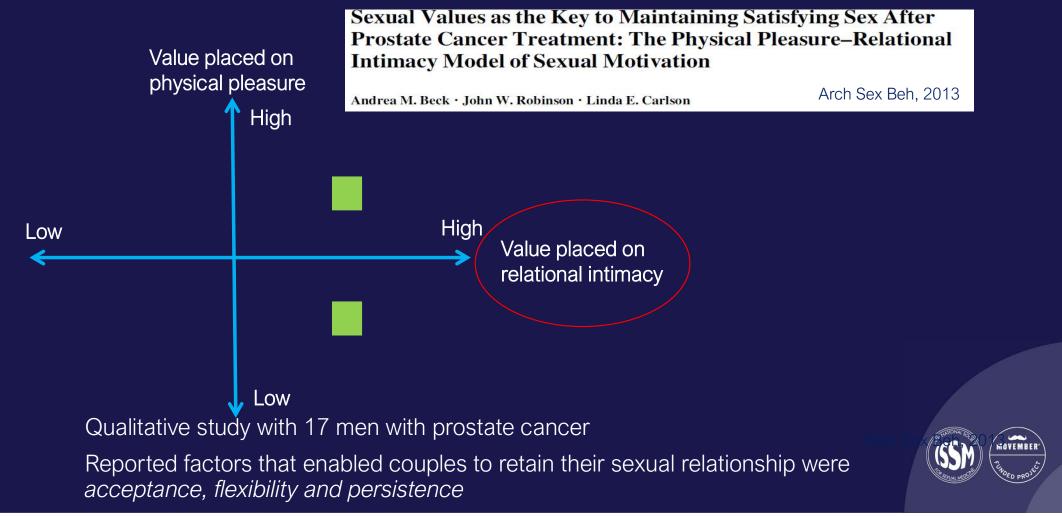
#### Review of 37 studies of couples with prostate cancer

- Maintaining connection
- Working as a team
- Not shielding each other from feelings
- Experimenting with new sexual activities
  - Re-eroticization of the body
    - · sensate focus exercises to reduce anxiety,
    - encouragement of flexibility to expand sexual repertoire beyond intercourse: oral sex, mutual masturbation, use of sex toys, visual stimuli "OUTERCOURSE" IS SEX!
    - Neuroplasticity: explore alternative erotic sensations (neck, ears, wrists, nipples, stomach, anus)
- Recognizing the importance of the partner's needs



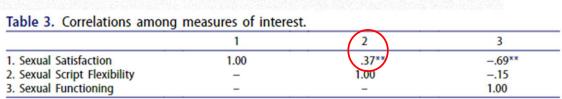


### Maintaining Connection

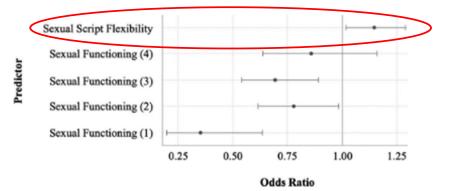


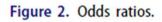
### Sexual Script Flexibility

#### 61 men with prostate cancer Crossectional study



Spearman correlations were calculated for correlations involving sexual satisfaction; a Pearson correlation was calculated between sexual functioning and sexual script flexibility. "p < .01.







McInnis et al., J Psychosoc Onc, 2023

### Mutuality is Important, but Generally Overlooked



10 patients and 9 partners interviewed Key result:

- Patients were unaware of partner's sexual needs
- This changed my practice



# Guidelines Principles and Statements Recognize the Importance of the Couple Approach



Why these Guidelines exist

#### Principle #3

The role of grief and mourning in couples' recovery of sexual intimacy has emerged as a path towards a new sexual paradigm despite sexual dysfunction.

#### Principle #5

Including the partner in sexual health counseling, if both partners agree, is preferable when men are partnered.

29/47 statements are addressed to both patients and partners



### Take Home Messages





- Include the partner in a discussion of sexual side-effects of prostate cancer and rehabilitation whenever possible
- Couples do best when they work together as a team
- Being able to express and tolerate each other's feelings of loss and grief bodes for a better sexual recovery
- Mutuality is key









# THANK YOU

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Complete our session survey to enter a raffle for a FREE one-year ISSM membership!







### Instructions



- Scan the QR code with your device or go to <u>www.issm.info/movember</u>
- This poll gathers insights to improve sexual health guidelines and resources in prostate cancer care through the ISSM and Movember partnership.







# THANK YOU