

Candid Conversations: Talking with Patients About Sexuality

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Medical risk factors for sexual problems

- Aging
- Medications: SSRI's, antiandrogens, antihypertensives, cardiac drugs, statins, steroids, chemotherapy
- Atherosclerotic vascular disease
- Pelvic trauma or surgery
- Neurological Disorder: Parkinson's, epilepsy, head or spinal cord injury, MS, spina bifida
- Endocrinological: diabetes, thyroid disorders, adrenal disorders, hypothalamic/pituitary disease, increased prolactin
- Infection/ sexually transmitted diseases
- Diabetes
- Psychological illness (depression, anxiety, schizophrenia)
- **Cancer**

Survey of women with breast cancer

N = 2220 surveyed:

▣ 1956 (88%) reported changes in sexual wellbeing:

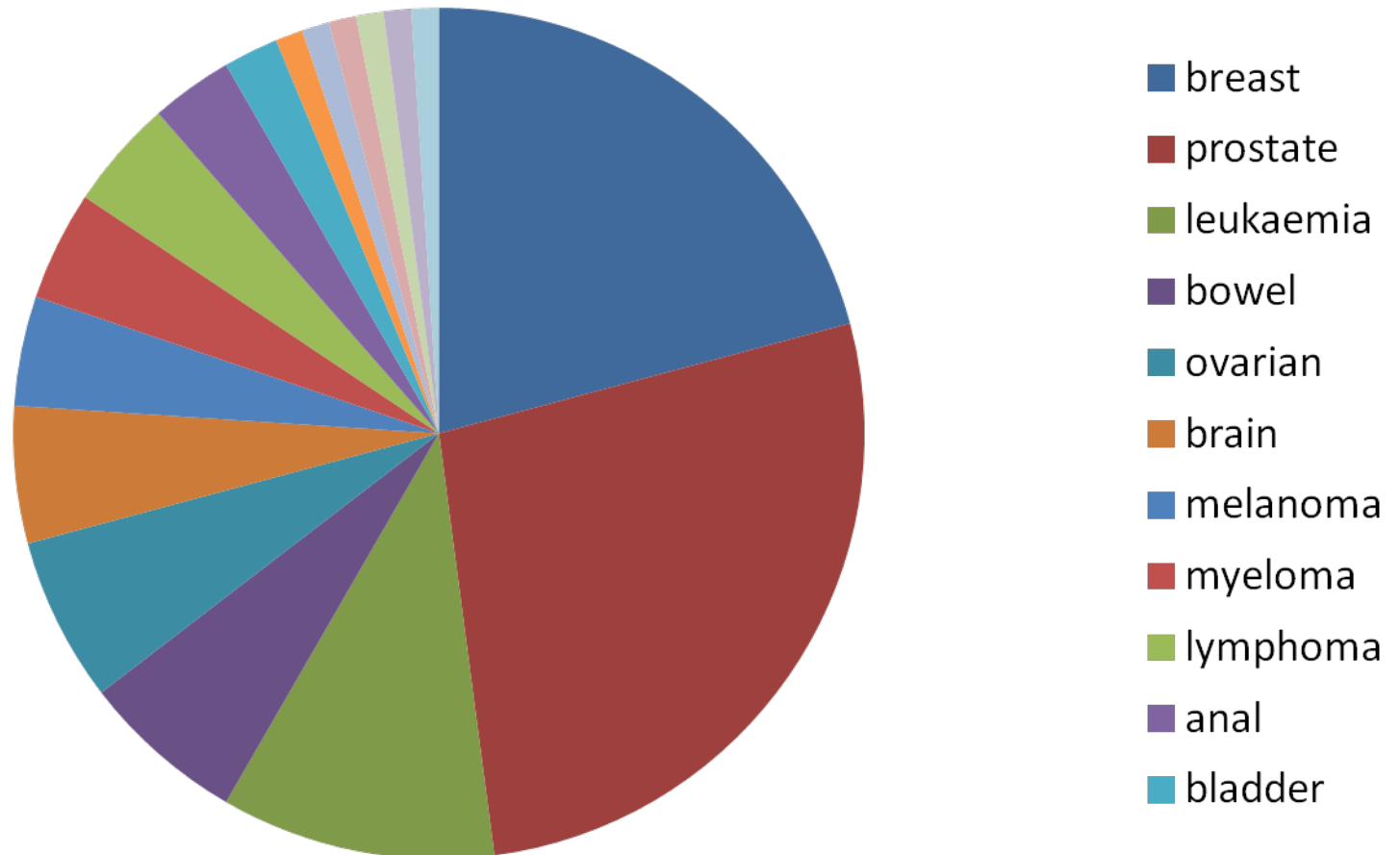
Decreases in:

▣ feeling desirable	73%
▣ intimacy	60%
▣ frequency of sex	78%
▣ sexual arousal	74%
▣ sexual pleasure	64%
▣ satisfaction with sex	62%
▣ energy for sex	76%
▣ interest in sex	71%

Ussher, JM, Perz, J. & Gilbert, E. (2012) Changes to sexual wellbeing and intimacy after breast cancer. *Cancer Nursing* 35(6), 456-465

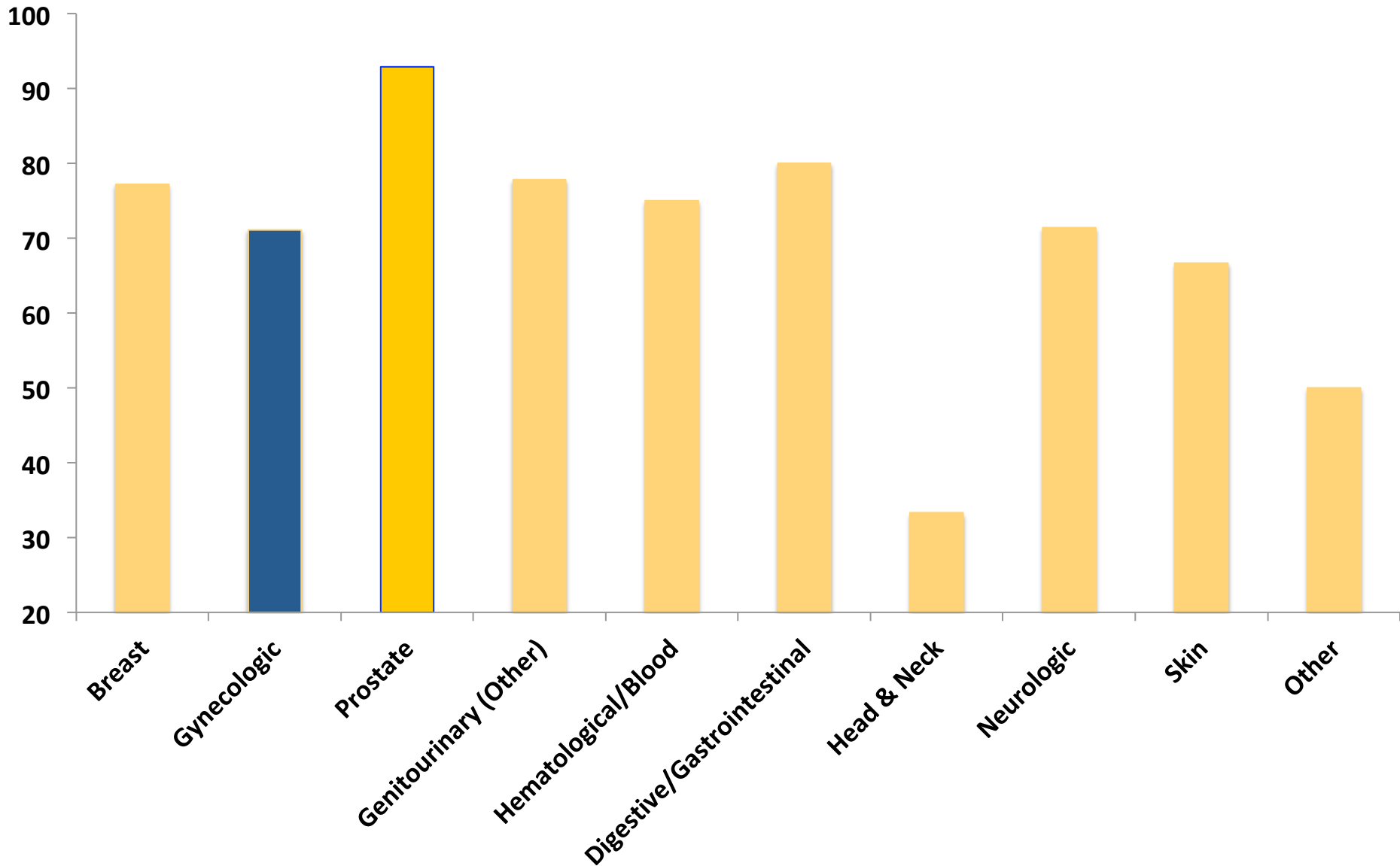
Changes to Sexuality across cancer types

Survey 942 people with cancer; 193 partners



ARC Linkage Project: CIs: Ussher, Perz, Gilbert; PIs: Wain, Hobbs, Kirsten, Mason, Batt, Sundquist. Partnership: UWS, CCNSW, NBCF, Westmead and Nepean Hospitals

Have your sexual activities changed since the onset of cancer?



Sexuality and cancer carers

- $N = 156$ carers (55 men, 101 women) - intimate partner of person with cancer
- 122 (78%) - cancer negatively impacted upon their sexuality and their sexual relationship
- Overall impact:
 - 76% 'non-reproductive' sites
 - 84% 'reproductive' sites

Hawkins, Y., Ussher, J.M., Gilbert, E., Perz, J., & Sandoval, M., Sundquist, K. (2009). Changes in sexuality and intimacy following the diagnosis and treatment of cancer: the experience of informal cancer carers. *Cancer Nursing: An International Journal for Cancer Care* 34 (4), 271-280

ARC Funded Project: Gendered experience of cancer carers (Ussher, Butow)

Communicating about sexuality with health professionals

Survey of women with breast cancer

N=2200

- 65% (1292) had not spoken to anyone
- 59% (1117) had not obtained any information
- 68% (1287) wanted information

Ussher, JM, Perz, J. & Gilbert, E. (2013) Information Needs Associated with Changes to Sexual Wellbeing after Breast Cancer. *Journal of Advanced Nursing* 69(2) 327-337

Cancer carers

Hawkins, Y., Ussher, J.M., Gilbert, E., Perz, J., & Sandoval, M., Sundquist, K. (2009). Changes in sexuality and intimacy following the diagnosis and treatment of cancer: the experience of informal cancer carers. *Cancer Nursing: An International Journal for Cancer Care* 34 (4), 271-280

- 80% had not discussed changes to sexuality with a health professional
- 37% (of 20%) indicated that they were 'satisfied' or 'very satisfied' with the discussion

Cancer type	Sexuality discussed by health professional
Prostate	50%
Breast	30%
Respiratory cancer	0%
Brain	33%
Pancreatic	33%
Gynaecological	29%
Multiple – sexual	21%
Colorectal/digestive	17%
Mesothelioma	17%
Multiple – non sexual	15%
Other	15%
Haematological	9%

Sexual communication after cancer

Survey 942 people with cancer; 193 partners

No discussion of sexuality with HPs:

People with cancer: 57.5% women; 32% men

Partners: 52.9% women; 72% men

Sexual cancers 50%; **non sexual cancers** 68%

Greater focus on men, and on sexual cancers

Gilbert, E., Perz, J. & Ussher, JM. (2016) Talking about Sex with Health Professionals: The Experience of People with Cancer and their Partners. *European Journal of Cancer Care* 25, 280-293 doi: 10.1111/ecc.12165

Sexual dysfunction was never mentioned as a side effect of my cancer treatment and yet it is the one side effect that has had a long term impact on the quality of my life.

42 year old woman, ovarian cancer

We were never informed about possible negative side-effects such as not being able to experience penetration.... as we had done for 8 years prior to diagnosis, surgery and treatment. I have always thought this problem was mine alone – no one had ever talked about it including other patients, doctors etc. **I now know that this situation happens to many women. If so then we should have been forewarned.** No wonder so many marriages fail when both are affected by the treatment consequences.

64 year old woman, breast cancer

Health Care Professional Perspectives

Interviews with 38 HCPs

- Awareness of sexual changes post- cancer: physical, psychological and relational
- Positioned such changes as having the potential to significantly impact on patient and partner wellbeing.
- Acceptance of importance of discussion of sexual changes within a clinical consultation, to alleviate distress, dispel myths, and facilitate re-negotiation of sexual practices.

Perz, J., Ussher, J.M. & Gilbert, E. (2013) Constructions of sex and intimacy after cancer: Q methodology study of people with cancer, their partners, and health professionals. *BMC Cancer*, 13, 270, 1-13, doi:10.1186/1471-2407-13-270

Health Care Professional Perspectives

Barriers to discussion of sex

- Personal, patient-centred, and situational factors as barriers to the discussion of sex within many clinical consultations.
 - absence of knowledge, confidence and comfort;
 - positioning sex as irrelevant or inappropriate for some people (*single, older, LGBT, CALD*).
 - limitations of the clinical context (privacy, time, responsibility).

Ussher, J. M., J. Perz, Gilbert, E., Wong, W.T, Mason, C., Hobbs, K & Kirsten, L. (2013). Talking about sex after cancer: A discourse analytic study of health care professional accounts of sexual communication with patients. *Psychology & Health* **28** (12): 1370-1390.

Sex and single women: Survey of women with breast cancer

Effect of breast cancer on the ability to enter a new relationship

	Count (N)
Body image/attractiveness concerns	77.2% (196)
Lack of confidence	66.5% (169)
Not feeling desirable	65.0% (165)
Lack of interest	53.5% (136)
Fatigue	46.5% (118)
Fear of rejection	46.5% (118)
Vaginal dryness	42.9% (109)
Upper body or other pain	22.8% (58)
Fear of sex will be different	20.9% (53)
Fear of physical pain	14.2% (36)
Fertility concerns	4.7% (12)
Feeling more attractive	3.5% (9)
Feelings of empowerment	0.8% (2)
Increased confidence	0.4% (1)

Ussher, JM, Perz, J. & Gilbert, E. (2012) Changes to sexual wellbeing and intimacy after breast cancer. *Cancer Nursing* 35(6), 456-465

Ageism, cancer and sexuality

“Whenever I seek information about my sexual wellbeing (or lack of it), the issue of my age bracket gets 'in the way'. **Evidently, I am not supposed to have an active and satisfying sex life at my age anyway.** However, I don't believe this to be correct, and I was enjoying sex, got relatively easily aroused and would often masturbate right up to early 2008. I was 61 then and don't believe that I was effectively much younger or very different from the individual I am now. I would very much like to resolve the problem(s) in regard to my sexual wellbeing, **as I firmly believe I should be able to continue to enjoy sex till the day I die. I miss it now”**

65 year old woman diagnosed with early breast cancer, 2 years post-diagnosis

Challenging ageism

“Prior to cancer we had a very, very healthy sex life and everything was brilliant and we had basically 10 years of great marriage and after that it had still been good but just the intensity has reduced substantially, ... before then, **it would be nothing to have sex five or six times a week, right and in different ways and places**”

Wayne, 66, partner, ovarian cancer

“We told all the doctors and different cancer people and everybody else that **we were like rutting rabbits, you know [laughs]**” Faye, 66, partner, prostate cancer

Ussher, JM, Perz, J. Gilbert, E., Wong, WT, Hobbs, K. (2013) Renegotiating sex and intimacy after cancer: Resisting the coital imperative. *Cancer Nursing* 36:6 454-462

Heteronormativity

I think my specialist was um, he was a conservative medico, and ***I don't think he was particularly comfortable with my lifestyle....*** It was all very, it was all quite cold and clinical and ***no real questioning or trying to understand my position as a gay male.*** There were a few things thrown in about men with partners but I got the impression that he was very, ***very strongly talking about female partners,*** and, you know, the husband and wife scenario and the family scenario, but that didn't apply to me, but that was the impression I got from the way he would describe and talk about impacts on partners and stuff like that ***even though he knew I was a single gay male.***

Scott, age 59, prostate cancer

Sexuality in Assyrian and Karen migrant women

Sexual discomfort and pain: a normal part of experience:

“I have two boys but I still don't like it, it's not interesting to me”

“We never enjoy”

“You have to have it whether you like it or not”

“They don't ask the wife “Did you enjoy? Did you finish?” or something like that. Just themselves, just finish it, enjoy, that's it”.

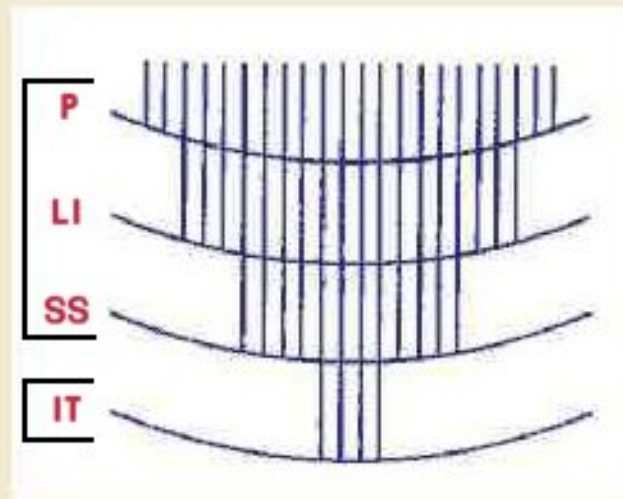
Ussher, JM., Rhyder-Obid, M., Perz, J., Rae, M., Wong, W.K.T., Newman, P. (2012) Purity, Privacy and Procreation: Constructions and Experiences of Sexual and Reproductive Health in Assyrian and Karen Women Living in Australia. *Sexuality and Culture* 16 (4) 467-485

Role of Health Professionals

- Acknowledge importance of sexuality to quality of life and relationship functioning
- Recognise association of sexual problems with physical and psychological illness
- Openness to discuss sexuality with patient – where relevant
- Challenging the coital imperative

The PLISSIT Model of Sex Therapy

(developed by Jack Annon)



P = Permission

LI = Limited Information

SS = Specific Suggestions

IT = Intensive Therapy

Brief Sexuality Related Communication.

Cancer Australia guidelines, women with breast cancer (2015)

Support a woman to discuss her feelings

Provide permission for a woman to discuss her sexual feelings and validate her experiences and concerns, noting that some women may feel guilt or embarrassment that they view their sexual wellbeing as a concern.

“Many women find that treatment for breast cancer changes their interest in sex and intimate relationships – this is more common than you may think, and it can have a big impact on your life.”

Support a woman to identify her sexual wellbeing concerns

- Support a woman to explore and prioritise her own sexual wellbeing concerns, noting that these may not be limited to physical symptoms.

“Many women experience side effects of treatments that impact relationships or sexual activities, such as loss of desire or pain. Do you feel like these or other symptoms are affecting your sex life or relationship?”

What do you (and your partner) find most concerning?”

Support a woman to consider her expectations regarding her sexual wellbeing

The changes to sexual wellbeing experienced may or may not be acceptable for a woman and her partner. Health professionals can encourage a woman and her partner to consider the ways in which they express sexuality and intimacy, and if they can explore alternative practices.

“Considering your symptoms, what would you (and your partner) consider an ideal outcome to be? How would you (and your partner) feel if you couldn’t achieve this?”

Provide information about what to expect

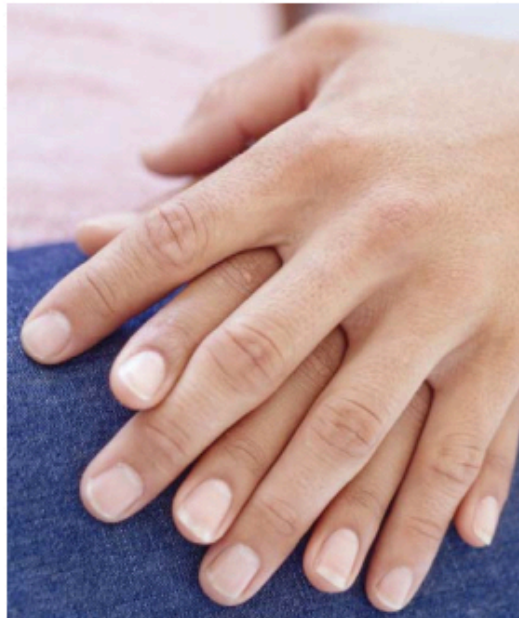
- Women should be aware that their sexual wellbeing concerns and priorities may change along the continuum of care associated with their treatment, their relationship with a partner, or their perception of themselves.
- Let the woman know that you are available to discuss sexual wellbeing at any stage and reinforce that their concerns are valid:

'You may not feel like thinking about or discussing your sexual wellbeing now, but you can always ask any questions you or your partner may have at any time in the future.'

How to respond ?

- Acknowledge problem.
- Treat any obvious physical cause
- Deal with it according to expertise
- Offer another appointment to discuss
- If the impact of symptoms remains a significant concern, consider referral to a local sexual health centre.
 - See the Sexual Health & Family Planning Australia website for links to state-based organisations:
www.shfpa.org.au.

Sexuality, Intimacy and Cancer



A Self-Help Guide for People with Cancer and their Partner

Perceptions of intervention – qualitative analysis

- **Increased awareness and communication about sex:**

“improved awareness of both our sexual needs”; “gave starting point for discussion”; “made me think about it more”; “brought sex into focus and put it on the agenda”.

- **Normalizing sexual change:**

- “I don’t feel so alone”; “I’m not the only one”; “it was useful to read about what other people have gone through”; “I found the recognition that there are problems with sexuality with cancer very helpful. It is better to be in a boat with others rather than trying to paddle alone through rough waters”

Perceptions of intervention – qualitative analysis

- **Legitimation of intimacy and non-coital sex.**

“being reminded that you can have intimacy that doesn’t involve sex”; “my husband seemed somewhat relieved to just kiss and cuddle”; “the act of intimacy has found a place in our relationship”; “the appreciation of just touching each other was good”

Perz, J. Ussher, JM. and The Australian Cancer and Sexuality Study Team. A randomised trial of a minimal intervention for sexual concerns after cancer: a comparison of self-help and professionally delivered modalities (2015) *BMC Cancer* 15(629), 1-16 doi: 10.1186/s12885-015-1638-6

Sexual renegotiation

- **Redefining sex:** as “not just penetration”
 - Exploring non-coital sexual practices: masturbation, mutual genital touching, or oral sex
- **Embracing intimacy:** cuddling, kissing, non-genital touching, massage, spending time together, caring, or talking.
- **Using sexual or medical aids:** Vibrators, lubricant, dilators, Viagra, penile injections, pumps and implants
- **Relationship communication:** Couples talking about sexual needs and concerns

Ussher, JM, Perz, J. Gilbert, E., Wong, WT, Hobbs, K. (2013) Renegotiating sex and intimacy after cancer: Resisting the coital imperative. *Cancer Nursing* 36:6 454-462



Many women experience sexual changes, but communication with health practitioners can reduce distress