

Women's sexual wellbeing in the context of cancer

Renegotiating sex outside the coital imperative

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Survey of women with breast cancer

$N = 2220$ surveyed (BCNA membership):

▣ 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, Perz & Gilbert (2012)

Centre for Health Research



Factors that affected sexual well-being (N = 1956)

	%		%
<input type="checkbox"/> Tiredness	71.0	<input type="checkbox"/> Reduced nipple sensation	35.4
<input type="checkbox"/> Vaginal dryness	63.3	<input type="checkbox"/> Pain during intercourse	33.4
<input type="checkbox"/> Hot flushes	51.2	<input type="checkbox"/> Anxiety about sex	28.6
<input type="checkbox"/> Feeling unattractive	50.8	<input type="checkbox"/> Early menopause	28.1
<input type="checkbox"/> Weight gain	48.8	<input type="checkbox"/> Appearance changes (eg. hair loss)	27.0
<input type="checkbox"/> Difficulty being aroused	45.8	<input type="checkbox"/> Pain in upper body	26.9
<input type="checkbox"/> Feeling uncomfortable exposing body	44.0	<input type="checkbox"/> Relationship changes	22.8
<input type="checkbox"/> Medication effects	39.0	<input type="checkbox"/> Fear	21.4
<input type="checkbox"/> Loss of confidence	38.4	<input type="checkbox"/> Loss of identity	17.0
<input type="checkbox"/> Depression/anxiety	37.8	<input type="checkbox"/> Anger	16.3
<input type="checkbox"/> Change in breast	37.6	<input type="checkbox"/> Lymphedema	16.3
<input type="checkbox"/> Orgasm difficulty	35.9	<input type="checkbox"/> Guilt	12.6
<input type="checkbox"/> Loss of sensation	35.8	<input type="checkbox"/> Feelings of shame	10.2

Horrible!! I'm 28 and have been married for 9 months and have had sex probably 4 times in that time. I used to enjoy it very much and now have no physical pleasure from it and barely ever do it. This has impacted on my identity as a woman and as a wife, has made me consider my partner having an affair because I am not able to satisfy him sexually

Ann, 29, breast cancer, hetero

Devastating. A complete shock, no one tells you that it ruins your sex life

Gina, 61, secondary breast cancer, hetero

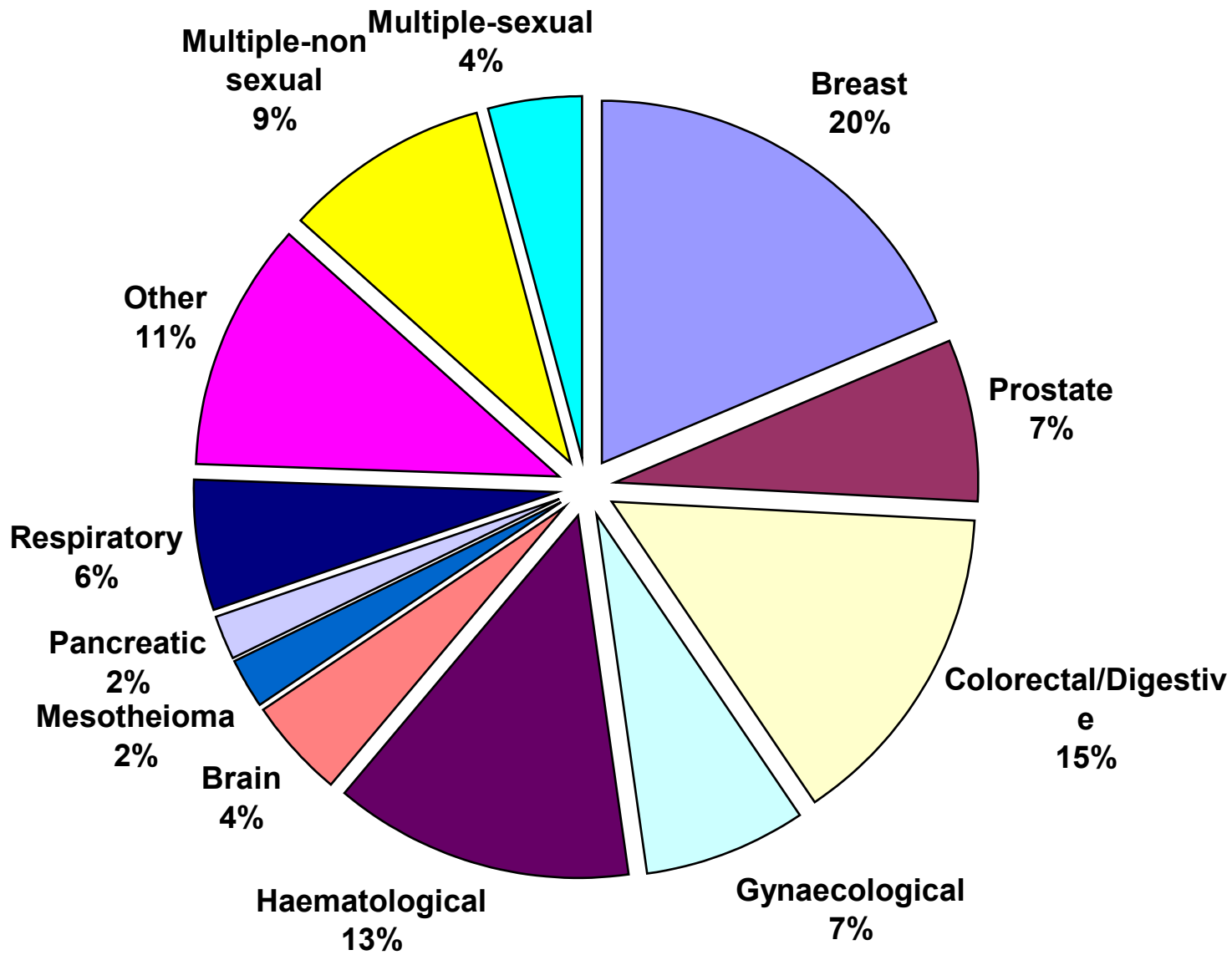
Sexuality and cancer carers

- $N = 156$ carers (55 men, 101 women) - intimate partner of person with cancer
- 122 (78%) - cancer negatively impacted upon their sexuality and their sexual relationship

 Lower desire; frequency; satisfaction

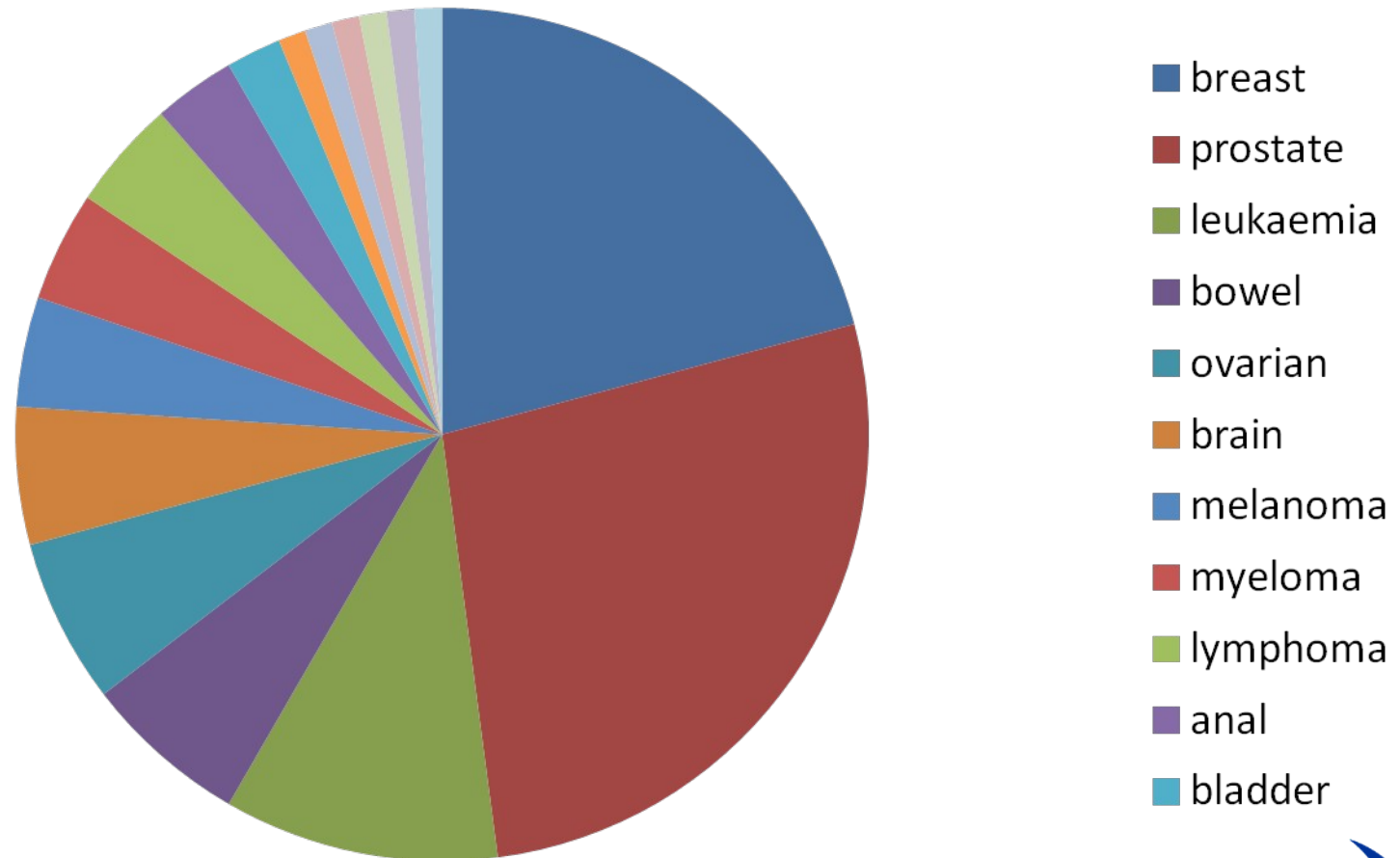
- Overall impact:
 - 76% 'non-reproductive' sites
 - 84% 'reproductive' sites

*ARC Linkage Project: Gendered experience of cancer carers; CIs: Ussher, Butow; PIs: Wain, Batt, Sundquist.
Partnership: UWS, USyd, CCNSW, Westmead Hospital*



Changes to sexuality across cancer types

Survey 942 people with cancer; 193 partners



Changes to sexuality across cancer types

Disruptions to sexuality

- decreased sexual desire and satisfaction
- repositioning of sex as a low priority
- sexual and bodily pain
- fatigue
- body image concerns (including, scarring, weight changes, and hair loss)
- Impact on sexual identity
- erectile difficulties (men)
- *Survey: 942 PWC, 193 partners; Interviews: 44 pwc; 39 partners*

ARC Linkage Project: CIs: Ussher, Perz, Gilbert; PIs: Wain, Hobbs, Kirsten, Mason, Batt, Sundquist

Partnership: UWS, CCNSW, NBCF, Westmead and Nepean Hospitals



Absence of desire

I'd rather do the washing but when it does happen,
it's pleasurable and no pain

Mindy 49, pwc, breast, hetero

The biggest effect is the instant menopause which
means loss of passion

Ursula, 47, pwc, ovarian, hetero

Sex positioned as secondary to survival

My focus was very strongly on survival. I didn't want to die (...) sex really didn't matter

Nelly, 57, pwc, lymphoma, hetero

I think other things sort of took over a bit more

Lara, 26, partner, leukaemia, hetero

Sex is probably the last thing on your mind at first

Ruby, 49, pwc, ovarian, hetero

Loss of identity and inadequacy

It's not the same person that you were (...) you lose your identity, I think. That's very depressing some days.

Cassie, 51, pwc, gynaecological, hetero

I used to enjoy it very much and now have no physical pleasure from it and barely ever do it. This has impacted on my identity as a woman and as a wife, has made me consider my partner having an affair because I am not able to satisfy him sexually

Ann, 28, pwc, breast, hetero

Body image concerns

I always cover up my leg during sex. [In a whispering voice] My God, if he should see that, that would be horrible. He would, he would lose his erection.

Sandra, 55, pwc, melanoma, hetero

I've put on so much weight. I'm the heaviest I have ever been since I had children

Carrie 51, pwc, breast, hetero

Sexual pain

It was unbelievably painful, I cannot tell you, it was unbelievably, it was excruciatingly painful to have intercourse. I literally couldn't bear to be touched *Irene, 61, pwc, anal, hetero*

I experienced a lot of dryness in the vagina, which causes me to be a little bit worried about the pain side of it

Henna, 59, pwc, ovarian, hetero

Coital Imperative:

Focus of research on cancer and sexuality

- “Sex” = coital sex (penis-vagina penetration)
 - Coital Imperative (*McPhillips et al 1999; Gavey et al, 2000*)
- Disruptions to coital sex = “sexual dysfunction”
- Consequences of coital “failure”:
 - All forms of intimacy can cease if penetrative sex is not possible
 - Attempting coital sex – even if it causes pain
 - Anxiety, feelings of inadequacy in men and women who can’t perform

Attempting coital sex

I am just trying to think when we started trying to have sex again, but I even went to the doctor and said, **“It feels like he’s got razor blades strapped to him”**

Sue, 57, breast cancer, hetero

- 91% of women engaging in coital sex 2 years after cervical cancer treatment, despite pain and low desire

(Jensen, 2004)

Sex = intercourse

He doesn't experiment a lot. He won't use toys. His argument is that you know we can do with our bodies better than what any toy can do. it's not so much variety in sex, ***it's the terror of playing that is there***

Helen, 64, pwc, kidney, hetero

Re-Negotiating Sex

Resisting the coital imperative



1. Resisting the coital imperative: *Re-Defining 'sex'*

I deeply reject the idea that sex is all defined in terms of the cock and what it does, where sex starts when the guy gets an erection and ends when he's had an orgasm and that's it.

Nina, 48, pwc, breast, poly-sexual

The view that sex is penetrative sexual intercourse, well, as a lesbian, it's not, not necessarily. It can be but it's often not

Bronwyn, pwc, 50, breast, lesbian

Re-Defining 'sex'

sex is more than just intercourse

Carl, 51, partner, lung, hetero

sex is not just penetration

Clinton, 57, partner, leukaemia, hetero

a couple can have a really strong relationship, an intimate physical one, without straight sex, like penetrative sex.

Brian, age 71, pwc, prostate cancer, hetero

Exploration of non-coital sexual practices

We were like, oh, two puppies playing together, even though I'm 59 and he's 74. Um, and even sort of simulated sex we'd get on top of each other and not actually have sex but, you know, sort of loving each other in a sex position

Nelly, 59, pwc, lymphoma, hetero



Use of sex aids and toys

Mindy (49, pwc, breast, hetero) - initially bought a vibrator to “keep all the (vaginal) muscles working”, but she and her husband also “had a bit of fun with it and now and again I’d think through the day, ‘Oh, I should go and do that.’”

Sexual aids are one way of both of us being able to participate which is important when the partner’s unable to have an erection.

Edith, 69, partner, advanced melanoma, hetero

Non-coital sexual activities - satisfying and pleasurable

Learning different techniques on how to do hand jobs and, and just things like that is interesting and fun, and our sex life is very good.

Ruby, 49, pwc, ovarian, hetero

Our sexual relationship has probably got better since my wife got sick, because we spend a bit more time in foreplay, to sidestep the vaginal dryness.

Henk, 63, partner, breast, hetero

2. Resisting the coital imperative: Embracing intimacy

Well, I guess we sleep together, so that's a good thing [chuckles], and cuddle up, and touch, and that sort of thing is always good.

Henna, 59, pwc, ovarian, hetero

It's the little things, like he knows if something is not quite right and he'll just come and stand next to me and give me a hug... that makes a difference

Kirsten, 24, pwc, lymphoma, hetero

Intimacy → closeness and normality

- Intimacy = Manifestation of closeness:

“being really very close together”

Charlotte, 66, partner, prostate, hetero

being “part of one another”

Pearl, 64, partner, prostate, hetero

- Produces increased closeness in the relationship:

“We’re closer than before the cancer, when it was more sexual, like more lust”

Russell, 39, partner, breast, hetero

3. Intersubjective nature of renegotiation: Relationship communication

We tend to be very open communicators in the bedroom. We're also probably on the fringe of on the top echelon of wanting to explore and to try different things. So we'll see, we tend to see if it'll if, if a) does it work, b) does it feel good, c) if both a and b work well that's great. If A and B don't work well then we don't do that one again. We stop.

Vicki, 36, partner, melanoma, lesbian

No communication – no renegotiation of sex

My husband doesn't hear very well, so the whole issue of asking for what you want or giving someone what they want, be it sexually or anything else, he finds extraordinarily difficult

Helen, 64, pwc, kidney, hetero

Positive relationship context

We've "always been very close," and "always hugged a lot," which meant that it was not very different after cancer, other than "maybe you appreciate it even more."

Emma, 52, pwc, breast, hetero

He's been fantastic, never put any pressure on me

Mindy, 49, pwc, breast, hetero

Couples who have been successful in maintaining a sexual relationship might be able to share the “secrets of their success”, providing guidance for the development of more successful interventions for those couples who struggle to maintain sexual intimacy after ... cancer treatment

Beck et al 2009, p.142

“Secrets of their success”

- **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,
- **Relationship communication:** Couples talking about sexual needs and concerns

Conclusions

- Impact of cancer on sexuality, and strategies of renegotiation, needs to be acknowledged by researchers and health professionals working with people with cancer and their partners
- Don't focus solely on coital sex
- Implications for broader analysis of sex and sexuality: coital sex is not always imperative - can be optional or negotiable, without loss of pleasure or satisfaction.