Author's response to reviews

Title: Perceived causes and consequences of sexual changes after cancer for women and men: A mixed method study

Authors:

Jane M Ussher (j.ussher@uws.edu.au)
Janette Perz (j.perz@uws.edu.au)
Emilee Gilbert (e.gilbert@uws.edu.au)
The Australian Cancer and Sexuality Study Team Team (cancerandsexuality@uws.edu.au)

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Author's response to reviews:

Editor's comments:
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1. Could the authors please add a table with a socio-demographic breakdown of patients' characteristics (including sex, age, type of cancer, length of relationship, time since diagnosis, sexual orientation, etc.)? 2. In tables 1 and 2, only summary data are given on changes in sexual functioning. Could the authors please add a table in which the transitions would be shown in more detail, by e.g. showing proportions of those who went from "good" to "bad", from "good" to "good", from "bad" to "good", and from "bad" to "bad"? By sex, age, sexual orientation, cancer type, length of relationship.

A new demographics table has been included (Table 1), incorporating socio-demographic breakdown of patients' characteristics (including sex, age, type of cancer, length of relationship, time since diagnosis, sexual orientation). Tables 2 and 3 have been revised providing the proportions of participants who have changed status on sexual satisfaction and sexual frequency pre-post cancer, in addition to the summary data.

2. In tables 1 and 2, the changes in sexuality were described by sex and type of cancer. Could the authors please also provide a description of the changes by time since cancer diagnosis? It would be interesting to see whether the disruption is different in an "acute" period right after cancer diagnosis vs. years later (in some cases up to 40 years later; for example, when the individuals and their partners have had the time to cope).

These changes have been added to table 2 and 3, as suggested.

3. Another interesting breakdown would be, for those in a relationship, by length of the relationship.

Length of relationship has been added as a variable in Table 2 and 3.
4. The age range of the individuals in the study was 19-87. The meaning of sexuality changes considerably from young to old age (and the authors also wrote that age was also sometimes considered as a likely co-factor for changes in sexuality), so a breakdown by age would also be meaningful in tables 1 and 2.

A breakdown of age has been added to table 2 and 3.

(points 1-4) Additional information on differences across demographic groupings has been added on p. 13 and p. 14:

p.13

“This pattern of a reduction in frequency occurred across all age, cancer type, years since diagnosis and relationship length categories: #55 years of age (#2 (1, 389) = 130.05, p < .001) and #56 years of age (#2 (1, 260) = 83.16, p < .001); reproductive (#2 (1, 564) = 209.76, p < .001) and non-reproductive cancers (#2 (1, 82) = 26.26, p < .01); #2 years since diagnosis (#2 (1, 274) = 83.03, p < .001) and #3 years since diagnosis (#2 (1, 375) = 130.06, p < .01); and #15 years in current relationship (#2 (1, 262) = 69.77, p < .01) and #16 years in current relationship (#2 (1, 366) = 141.74, p < .001).

p. 14

This finding was consistent across all age, cancer type, years since diagnosis and relationship length categories: #55 years of age (#2 (1, 370) = 140.34, p < .001) and #56 years of age (#2 (1, 250) = 84.15, p < .01); reproductive (#2 (1, 541) = 217.36, p < .001) and non-reproductive cancers (#2 (1, 76) = 10.32, p < .01); #2 years since diagnosis (#2 (1, 262) = 91.46, p < .001) and #3 years since diagnosis (#2 (1, 359) = 133.99, p < .001); and #15 years in current relationship (#2 (1, 250) = 81.92, p < .001) and #16 years in current relationship (#2 (1, 354) = 140.51, p < .001).

5. For the in-depth interview part of the study, the authors chose 44 out of the 274 individuals who responded positively to the invitation. How representative were these individuals for the patients with cancer? And, is it correct that this is the only part of the study where also partners of cancer patients could take part?

The 44 interviews were conducted with people with cancer – not partners. This has been clarified on p. 10, with the inclusion of the phrase: “We purposively selected 44 people with cancer for interview” omission of the sentence: “The participants were not matched pairs; individuals could participate in an interview regardless of whether their partner was taking part”.

Analysis of the experiences of partners is published elsewhere, as this analysis was part of a larger mixed methods project examining the construction and experience of changes to sexuality after cancer for patients and partners (as noted on p.7, line 129-130).

Further details about the demographics of the interview sample have also been added, as outlined below.
6. What were the characteristics of the patients who experienced negative sexual changes after a cancer diagnosis, compared to patients without negative changes?

Additional descriptive text detailing differences between those participants who experienced negative sexual changes after cancer compared to those without negative changes is presented on pages 13 and 14.

p. 13 “Participants with a reproductive cancer type were significantly more likely to report that sex occurred never or rarely after cancer (52.4%) compared to 32.5% of those with a non-reproductive cancer ($\chi^2 (1, 648) = 11.42, p < .001$), but no differences were found in these reports according age, years since diagnosis and years in current relationship”.

P14. No differences were found in the proportion of participants after cancer rating the sexual relationship as unsatisfying according to age, years since diagnosis and years in current relationship, although participants with a reproductive cancer type were significantly more likely to report unsatisfying sexual relationships after cancer (49.9%) compared to 35.9% of those with a non-reproductive cancer ($\chi^2 (1, 621) = 5.36, p = .021$).

7. The Discussion is interesting but difficult to follow. Could the authors please structure it differently? For example: general findings, strengths/limitations, comparison with the literature, clinical implications, conclusion.

The discussion has been restructured as suggested: general findings and comparison with literature; strengths and limitations; clinical implications; conclusion.

8. Please explain all abbreviations in tables (as a footnote).

A key to the abbreviations has been provided as a footnote at the end of Table 4.

9. Please format the reference list in a consistent manner, including listing of journal names for all references.

The reference list has been reformatted as suggested

Reviewer: Marieke van Leeuwen

Discretionary revisions:
1. On line 141 is referred to one person being poly-sexual. Although maybe not exactly the same for this person, I would refer to this person as being bisexual.

The participant self-identified as ‘polysexual’, and expressly rejected the term ‘bisexual’. We have clarified this by inserting the term ‘self’ into the phrase “the remainder self-identifying” (line. 142).

Minor Essential Revisions:
2. Line 394 “carer” should be “cancer”
This revision has been undertaken

3. Page 43 in row “Feeling unattractive” “Hickmais” should be “Hickman”
   This revision has been undertaken

4. Page 47 in row “Renegotiating or redefining sex” what is PWC? And: “though
   I’m 59” and “(W, 57, hetero, lymphoma)” The ages are not corresponding.
   This revision has been undertaken, by removal of ‘pwc’ and correction of the age
   of the participant.

Major Essential Revisions:

5. Line 98 to 104 the researchers describe that a problem with previous research
   is the underrepresentation of LGB people and single people. Although the
   authors do include 33 LGB people and 106 single people (on a sample size of
   757 people), these people are no subject of discussion in the result section. If the
   authors do want to continue to make this statement, they also should describe
   these populations in the result section. In the case of the LGB people they of
   course have to make a remark regarding the small group of LGB people included
   in their study and how this will influence the generalizability of their findings.

   The comments in the introduction on LGB people and single people have been
   deleted, as sub-analysis was not conducted on these populations, due to sample
   size.

   In the discussion of the inclusion of LGB individuals in the strengths and
   limitations section of the discussion, the issue of small sample size precluding
   sub-analysis is noted:

   “As sample size of LGB individuals precluded sub-group analysis, further
   research is needed to examine the causes and consequences of sexual changes
   and renegotiation after cancer within a larger population of gay, lesbian, bisexual,
   and transgender individuals, who have been described as an “overlooked health
   disparity” [126, p1009] in the context of cancer”.

6. In line 110 to 120 the authors describe the MDI model. Especially from line
   113 to 118 the description of the model is rather vague. I would like to see a
   more detailed explanation of the model. Maybe an example would make the
   model more clear to people not familiar with this model.

   The description of the MDI has been clarified, and an example given, as
   suggested (p.6-7):

   “We are adopting an integrative material-discursive-intrapsychic (MDI) model [64,
   67], which conceptualises sex and sexual well-being as a multi-faceted construct
   [68], wherein the effects of cancer and its treatment result from the
interconnection of material, discursive and intrapsychic factors. This includes the materiality of embodied sexual changes after cancer, including changes in desire and functioning, and anatomical changes resulting from cancer treatment, as well as the material context of people’s lives, such as whether they are in a relationship or have partner support; changes which occur at an intrapsychic level, such as reductions on psychological well-being, and changes to sexual self-schema [69], identity [70], or body image [61]; and socio-cultural representations and discourses which shape the experience and interpretation of sex, telling us what is ‘normal’ and ‘abnormal’ sexual behaviour [55]. In contrast to bio-psycho-social models of experience [71], which conceptualise biology, psychology and social factors as independent, the MDI model conceptualises material, intrapsychic and discursive factors as inseparable. For example, the experience of material changes to sexual functioning which result from prostate cancer treatment – erectile dysfunction and reductions in sexual desire - is inseparable from intrapsychic responses to such changes – feelings of loss of manhood and depression [5] – and the discursive context which positions erectile functioning as sign of masculinity, and performance of coital sex as ‘real sex’ [72].”

7. Line 127 Men are underrepresented in this study as well as patients with non-reproductive cancer. Further, breast cancer patients are overrepresented. As I understand that this problem is not easy to fix, I would like that the authors name this as a limitation of the study in the discussion section and speculate how these under-/overrepresentations affect their results.

This issue has been referred to in the strengths and limitations section of the discussion:

“The over representation of women with breast cancer, and low representation of men in the sample is also a limitation. However, the absence of a notable pattern of significant differences across cancer type or gender suggest that this does not undermine the study findings to a marked degree”.

8. Participants Could the authors say something about the disease status of the patients, how many are disease free, with a recurrence etc.?

This information is provided in Table 1, as stage of disease.

9. Line 248. 6.7% of women and 4.3% of men rated their sexual relationship before cancer as unsatisfying. I can imagine that in retrospect life before cancer seems way better than life after the diagnosis. This makes me wonder how many people in the general population rate their sex life as unsatisfying. Can the authors discuss the issue retrospective data collection in their discussion, and to what extent they think this could have influenced their findings?

The level of sexual dissatisfaction prior to cancer is comparable to Australian
population norms, as assessed by the recently published Australian Study of Sex and Society. This has been acknowledged in the following inclusion on line 362-363:

“Whilst reported levels of sexual dissatisfaction prior to cancer were comparable with Australian population norms [79]...”

The issue of retrospective data collection is discussed as a limitation of the study in the discussion:

“The retrospective nature of data collection, asking participants to report on perceived changes pre-post cancer, was also a potential limitation; prospective analysis of sexual changes through the course of diagnosis and treatment would overcome this limitation”.

10. Figure 2 In this figure a distinction is made between surgery and medication. Whether sexuality is affected by surgery or medication is very cancer treatment dependent. E.g. In breast cancer patients tamoxifen treatment has a major impact, while in gynecological cancer patients surgery has a more profound impact. (Of course also breast cancer patients are affected by surgery as well and gynecological cancer patients by chemotherapy.) In prostate cancer patients not receiving hormonal therapy surgery has the strongest impact. Since the type of cancer influences in what way the treatment has an impact on sexuality and the cancers are not evenly represented in this study, I would not make a distinction between surgery and medication. I would simply say cancer treatment, because else it suggests that for men surgery is more important than for women in affecting sexuality, whilst this number says more about the type of cancers included in the study and the overrepresentation of for instance breast cancer.

The suggested revision has been made, with ‘cancer treatment’ being included as a perceived cause of sexual changes, rather than specific forms of treatment.

11. Line 338 “Kissing and petting/caressing were reported to be the most common sexual activities after cancer for both women and men, suggesting that coital and genital sexual activities are being replaced by non-genital intimacy for some couples.” As all intimacy, except for sex toy use, is reduced after cancer, the quantitative findings do not support the hypothesis that “coital and genital sexual activities are being replaced by non-genital intimacy for some couples.” The qualitative data do support this hypothesis, so I would suggest the authors to change the argumentation they use in favor of this hypothesis.

This section (line 390) has been revised as suggested:
Kissing and petting/caressing were reported to be the most common sexual activities after cancer for both women and men. When viewed in conjunction with a face-value increase in men’s reports of the use of sex toys, and qualitative accounts of the exploration of new sexual practices, or non-genital intimacy, this indicates sexual re-negotiation [83] or flexibility [84] following cancer on the part of some couples.

12. Line 463 “Equally, whilst previous research has focused on the heterosexual population, the present study included individuals who identified as gay, lesbian and polysexual, confirming that sexual changes also affect this hitherto “hidden population”. First of all I would refer to the polysexual as bisexual. More importantly, the LGB people are not described in the result section. This paragraph suggests that the authors gave some attention to this group in their findings. Or the authors give some attention to this group in the result section or they do not make a statement regarding the inclusion of LGB people in their study.

This section has been revised, as noted in point 5, above. Polysexual has been replaced by the term 'bisexual' in this context.

13. Discussion Limitations The study depends heavily on memories of the patients regarding their sex life before cancer diagnosis, on average 5 years ago. I would like to see that the authors discuss how this might have affected their findings.

This issue has been addressed above.

14. Table 3, 4 and 5 Could the authors add time since diagnosis and whether patients are disease free in the description of the patients.

This issue has been addressed.

Reviewer:Sally Taylor
Reviewer's report:
Major Compulsory Revisions

The authors provide little detail about their chosen method of analysis and how this analysis was conducted.

Further detail is provided about the analysis (p. 227-256)

The analysis was conducted using theoretical thematic analysis 36, using an inductive approach, with the development of themes being data driven, rather than based on pre-existing research on sexuality and cancer. In the analysis, our aim was to examine data at a latent level, examining the underlying ideas,
constructions and discourses that shape or inform the semantic content of the data, interpreted within a material-discursive-intrapsychic theoretical framework. All of the interviews were transcribed verbatim. One of us read the resulting transcripts in conjunction with the audio recording, to check for errors in transcription. Detailed memo notes and potential analytical insights were also recorded during this process. A subset of the interviews was then independently read and reread by two of us to identify first order codes such as “embodied changes”, “emotional distress”, “relational issues”, “interactions with health professionals”, or “support needed”. The entire data set was then coded using NVivo, a computer package that facilitates organization of coded qualitative data. All of the coded data was then read through independently by two members of the research team. Codes were then grouped into higher order themes; a careful and recursive decision making process, which involved checking for emerging patterns, for variability and consistency, and making judgements about which codes were similar and dissimilar. The thematically coded data was then collated and reorganized through reading and rereading, allowing for a further refinement and review of themes, where a number of themes were collapsed into each other and a thematic map of the data was developed. In this final stage, a number of core themes were developed, which essentially linked many of the themes. These included the impact of sexual changes on self and identity, and communication with health professionals, reported elsewhere, as well as “renegotiating sex and intimacy”, the focus of the present paper.

More detail is needed about the demographics of the subsample of participants who were interviewed.

Further information is provided about the subsample of interviewees (line 195-200):

“We purposively selected 44 people with cancer for interview (23 women, 21 men) representing a cross section of cancer types and stages, gender, and sexual orientation. The average age of interviewees was 54.6 years, with 50% experiencing a reproductive cancer (prostate, breast, gynaecological, anal) and 50% a non-reproductive cancer (colorectal, melanoma, lymphoma, leukaemia, kidney, bladder, and brain).”

The authors do not provide any details about the length of interviews nor do they provide an explanation as to why some interviews were conducted over the telephone and others face to face. Were participants given the option to choose between a face to face interview or one conducted over the telephone? Were there any specific reasons why seven participants were interviewed face to face.

It would be helpful if the interviewees provided an explanation as to why two interviewers conducted the interviews as it is generally considered best practice for just one interviewer to be present to avoid intimidating the participant.
Clarification of the above points has been made (line 198-2009):

“Individual semi-structured interviews, lasting on average 60 minutes, were conducted by either a woman or man interviewer, on a face-to-face (7) or telephone basis (72). Participants were given a choice as to the mode of interview (telephone or face to face), and asked if they had a preference about the gender of the interviewer: the majority had no preference for gender, but chose telephone modality. Telephone interviews have previously been recommended for interviews regarding sensitive, potentially embarrassing topics [75], such as cancer and sexuality, and pilot interviews indicated that they were an effective modality to utilise in this study.”

Minor Essential Revisions

The authors state that a strength of this research is that it includes participants with reproductive and non-reproductive cancers. The majority (85%) of the sample however is made up of participants with reproductive cancers. Could the authors say something about whether these figures are representative of the people approached to take part in the study or the general population. The figures for GI and respiratory cancers for example seem a little low compared to current statistics.

The issue of representativeness of the sample is discussed on line 475 onwards: The over representation of women with breast cancer, and low representation of men in the sample is also a limitation. Whilst breast cancer is the most common cancer affecting women, there is an under-representation of prostate cancer, the most common cancer affecting men, as well as other common cancer types [1], including respiratory, skin, gastro-intestinal and head and neck cancers. This may be because individuals with non-reproductive cancers are less likely to volunteer for a study on sexual changes, as well as effective strategies of participant recruitment on the part of breast cancer organisations. Future research which specifically targets non-reproductive cancers is needed to examine the subjective experience of sexual changes after cancer, and examine whether the present findings can be generalised.