Author’s response to reviews

Title: Need for Information, Honesty and Respect: Patient Perspectives on Health Care Professionals Communication about Cancer and Fertility

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Version: 1 Date: 07 Sep 2017

Author’s response to reviews:

Thank you for reviewing our paper and for the referee comments. We have now revised the paper addressing all of the comments and suggestions, and are resubmitting the paper for your consideration.

We summarise each of our responses below, and enclose a revised paper with track changes identifying our changes, and a version with changes accepted.

Major

* There are results in the methods section, for example, 56.7% had breast cancer etc. that whole paragraph with numbers goes in the results, not in the methods

Response: We have moved the details of participants to the results section

* It is very odd that 78 interviews would have been done. Saturation would typically be reached way before 78, indicating that this was not done in a rigorous manner. This needs to be justified.

As noted on . 9: “Purposive sampling [46] was used to select interview participants who had expressed concerns about fertility after cancer, with the aim of gaining insight into the experience of people across gender, age groups, cancer type, relationship contexts, and parenthood status (parous/nulliparous)”.

In order to be able to examine commonalities and differences across these groupings, this required a sample size that was relatively large for qualitative research. We did not reach saturation before 78 interviews.

* Again, Final themes were… that needs to be in the results section not the analysis section
Response: the paragraph reporting the final themes has been moved to the results section

* Even if the names are made up, they need to be removed. It is more common to say Female Patient, Age 45. Not Abigail or Harry.
Response: All names have been removed. At the end of the paragraph on the final themes, we have added the sentence “In the presentation of results, gender, age and cancer type is indicated for longer quotes.”

* The results section is too long.
Response: We have edited the results section to shorten it.

* The discussion needs to tie this back to something actionable- what does this mean for policy or practice? This would help to justify why this needs to be published.
Response: We have added a number of additional sections to the discussion to tie the findings back to policy and practice.

These findings have a number of implications for clinical practice and policy. Reports of absence of discussion of fertility concerns by a substantial proportion of clinicians suggest a deficit in institutional policy and practice guidelines to assist HCPs with such discussions [21]. It has previously been reported that no single professional group possesses all of the skills or information necessary to effectively address the complexity of fertility concerns after cancer [71], and current clinical guidelines do not stipulate whose role it is to provide oncofertility care [21]. Agreement on a standardised referral pathway to assist in the provision of such care [24], Many HCPs working in oncology have a low level of knowledge about fertility preservation options or appropriate facilities [71]. There is also evidence that many HCPs hold negative beliefs about the importance of fertility for their patients [21], as reported in the present study.
Additional training is needed to address such beliefs and to equip HCPs with skills to address oncofertility concerns [72-74], and many clinicians report interest in such training [21, 24]. In particular, it is vital that physicians providing cancer treatment should be aware of the effects of treatment on fertility and of ways to minimise these effects [75].

As the psychosocial experience of infertility has been reported to be different across genders [76, 77], with higher levels of fertility related distress reported in women cancer survivors [1, 3, 32], it is important that fertility information is gender specific, and sensitive to the gendered concerns of patients and their partners [76]. This includes awareness of the potential impact of compromised fertility on the gender identity of women [57, 78] and men [79, 80], and the gendered experience of fertility preservation, including difficulties in the collection of sperm [17], or the experimental nature of fertility preservation, when IVF is not possible, for women [81]. It has been argued that there is a need to bridge the gap between the two separate disciplines of oncology and fertility preservation, through the creation of multidisciplinary teams that include oncologists, nurses in the specialities of oncology and infertility, social workers, reproductive endocrinology and infertility specialists, andrologists, and embryologists, working together to improve the outcomes for cancer survivors [82]. Continued education about the rapidly changing field of fertility preservation techniques [81], as well as peer support and consultation [24], would be suitable in such a context. However, clarification of whose role it is to address oncofertility within a multidisciplinary team, is needed, as not all members of a team can be expected to raise the issue [21]. There is evidence that lack of availability of fertility counselling and fertility preservation services can act as a barrier to referral and utilisation of services [21]. This suggests that further efforts need to be made to raise awareness of the importance of oncofertility for service providers and policy makers, who make the decisions about resource provision within health systems.

Minor
* Through the manuscript, especially in the introduction, there are run on sentences. Sentences longer than 30 words should be avoided.

Response: We have shortened a number of sentences throughout the manuscript.

* The paper talks about past research being limited by sample size, yet this study has over 800. There is a debate as to whether or not that is still small. I would temper the language and present it as a more comprehensive study but it is not nationally representative or even the size of some other cancer studies like the CCCS.

Response: We have modified the discussion of sample size in the introduction (P.6):
Previous research has also been criticised for being small scale, with participants primarily recruited from a single clinical site, and focusing on a one tumour type - primarily cancers that affect the sexual organs [9, 33]. There is evidence that a wide range of cancers and cancer treatments may impact upon fertility [7, 45], and that fertility related distress does not differ across tumour type [4]. This suggests a need for a more comprehensive study across a broad range of cancer types and clinical sites, to examine the experience of patient-health care provider communication about cancer related fertility concerns.

We have removed the word ‘large’ from the sentence “Eight hundred and seventy-eight people living with cancer (693 women, 185 men) took part in a mixed-method study which examined the construction and experiences of fertility after a cancer diagnosis” (p. 7).

In the limitations section we have added the sentence: The limitations include the fact that the sample was not nationally representative,

* In the introduction the aim is in two paragraphs, it should only be in the later.

Response: We have removed the aim from the first paragraph

* Was there an incentive given?

Response: We have added the following sentence to p.7.

Participants were given a modest reimbursement for expenses, in the form of a gift voucher for $25 (AUD).

* Why are some quotes in italics and some not?

None of the quotes are in italics. The only use of italics is in a level 3 subheading on p. 15

Reviewer #2:

Thank you for the opportunity to review this article reporting the qualitative findings from interviews with participants in a larger survey study. The authors have clearly articulated their aims and research questions. The methods are appropriate and well described demonstrating a high level of rigour in the qualitative analysis.
Results of this study confirm and extend previous findings, and are indicative of a high level of distress amongst some patients related to their experience of (or lack of information about) fertility preservation prior to commencing their anti-cancer treatment(s). Interestingly, the authors indicate a higher level of health literacy regarding reproductive outcomes in patients who were informed about fertility issues prior to treatment. I did wonder if health literacy was measured in anyway or if these comments reflect only the participants ability to demonstrate greater knowledge about fertility issues?

Response: We did not use a health literacy measure, so have clarified the sentence on page 20 to read:

In combination, this was reported to increase their knowledge and confidence in discussing cancer related infertility, providing the sense of self-efficacy that is essential in coping [49-51].

Given that these data complement a larger survey study, I would have liked to see a greater integration of the qualitative findings with those of the quantitative survey results. At the present time, the results of both components of the study have been treated independently. Could the authors please comment on the rationale for this decision and whether there is an opportunity to use the complete datasets to triangulate results toward stronger recommendations regarding improvement in service provision for these participants.

Response: In this paper we have combined the quantitative and qualitative data associated with communication with health professionals about fertility concerns – the focus of the paper. The data in the larger survey is not concerned with this subject matter, so is not included in this paper. To include all of the data analysis in one paper would make the paper extraordinarily long – reviewer one has suggested that the current analysis is too long, and we have edited it as a result.

The discussion places these findings in the context of the broader literature regarding cancer and fertility. While there is a suggestion that a group of health care professionals knowledgeable in fertility preservation be included in the cancer MDT, the comment lacks any discussion of the feasibility of this suggestion. Could the authors please comment more pragmatic or alternative approaches to improving services for, or at least discussion of, fertility preservation options and cancer treatment implications with patients in a more timely way. For example, could this be achieved by improved education and training for oncology staff in how to have these discussions and what the options are, as well as awareness of fertility concerns and the impact of making assumptions about reproductive preferences of their patients?

Response: We have addressed these issues in the revised discussion:
These findings have a number of implications for clinical practice and policy. Reports of absence of discussion of fertility concerns by a substantial proportion of clinicians suggest a deficit in institutional policy and practice guidelines to assist HCPs with such discussions [21]. It has previously been reported that no single professional group possesses all of the skills or information necessary to effectively address the complexity of fertility concerns after cancer [71], and current clinical guidelines do not stipulate whose role it is to provide oncofertility care [21]. Agreement on a standardised referral pathway to assist in the provision of such care [24], Many HCPs working in oncology have a low level of knowledge about fertility preservation options or appropriate facilities [71]. There is also evidence that many HCPs hold negative beliefs about the importance of fertility for their patients [21], as reported in the present study. Additional training is needed to address such beliefs and to equip HCPs with skills to address oncofertility concerns [72-74], and many clinicians report interest in such training [21, 24]. In particular, it is vital that physicians providing cancer treatment should be aware of the effects of treatment on fertility and of ways to minimise these effects [75].

As the psychosocial experience of infertility has been reported to be different across genders [76, 77], with higher levels of fertility related distress reported in women cancer survivors [1, 3, 32], it is important that fertility information is gender specific, and sensitive to the gendered concerns of patients and their partners [76]. This includes awareness of the potential impact of compromised fertility on the gender identity of women [57, 78] and men [79, 80], and the gendered experience of fertility preservation, including difficulties in the collection of sperm [17], or the experimental nature of fertility preservation, when IVF is not possible, for women [81]. It has been argued that there is a need to bridge the gap between the two separate disciplines of oncology and fertility preservation, through the creation of multidisciplinary teams that include oncologists, nurses in the specialties of oncology and infertility, social workers, reproductive endocrinology and infertility specialists, andrologists, and embryologists, working together to improve the outcomes for cancer survivors [82]. Continued education about the rapidly changing field of fertility preservation techniques [81], as well as peer support and consultation [24], would be suitable in such a context. However, clarification of whose role it is to address oncofertility within a multidisciplinary team, is needed, as not all members of a team can be expected to raise the issue [21]. There is evidence that lack of availability of fertility counselling and fertility preservation services can act as a barrier to referral and utilisation of services [21]. This suggests that further efforts need to be made to raise awareness of the importance of oncofertility for service providers and policy makers, who make the decisions about resource provision within health systems.
I noted two points for correction:

Page 13 line 30 fertility preservations - remove s Page 21, line 17 - cancer type for participant is undefined.

Response: These typos have been corrected

Overall, this is an excellent paper.