Author's response to reviews

Title: The structure and demographic correlates of cancer fear

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Version: 3
Date: 27 June 2014

Author's response to reviews: see over
Dear Dr Downing,

RE: Cancer fear in older adults (ID: 1368318941125743)

Thank you for the opportunity to revise our manuscript. We would like to thank the reviewers for taking the time to read the manuscript and give their feedback. We have carefully considered their comments and have made some substantial changes to the manuscript, which are detailed below.

We look forward to hearing from you,

Yours sincerely,

Charlotte Vrinten, BSc, MSc
Reviewer 1 (Nathan Consedine)

1. First, given prior findings from Europe and the US, there is no particular reason to suspect that cancer fears would be any less prevalent in a comparably westernized healthcare context. Thus, some work is needed to ensure that the manuscript’s primary “additive” contribution is appropriately highlighted. What should the reader know at the end of the paper that they do not currently appreciate? As is noted below, there are some issues with the contributions based around (a) distinguishing among fear-like constructs and (b) evaluating whether demographics equally predict these three constructs. Thus, the manuscript would benefit from more clearly highlighting what is known as a result of the work that was not known before, perhaps by talking in slightly greater detail about possible differences in the UK provision context.

Cancer fear continues to be an important issue worldwide, but almost all research into cancer fear has used it as a means to an end, for example, to predict cancer screening uptake. Studies that have examined fear in itself are nearly all qualitative or conducted in undergraduate samples for whom the threat of cancer is less relevant due to their young age. Given the frequency of public statements about cancer fear, it is clearly a societally important matter. Understanding who is experiencing cancer fear most, and which of its elements are most striking, seem to us important issues.

To address the issues that were highlighted by the Reviewer, we have added two paragraphs to the Background section; to explain the rationale of the study more clearly and to describe what is currently known about the topic and what this paper adds to our current knowledge.

2. Second, although the manuscript is correct in stating that “fear has a complex architecture,” the rationale for the measurement of three potentially distinct constructs (cancer fear, distress/discomfort, and worry) with three single items is probably suboptimal as it currently stands. In addition to creating a concern about the validity of single items as measuring a construct, it is unclear that these three constructs are, in fact, the correct ones. Admittedly, the suggestion that these items are indexing separate processes gains some support from the moderate correlations among both the items themselves as well as with general anxiety, but without a theoretical base or framework the work risks appearing excessively opportunistic. One possibility is that the authors use work from either the extensive general psychological literature addressing the components of worry and/or that they draw from cancer screening related work that distinguishes among worry-like constructs (Consedine, Adjei, Ramirez, & McKiernan, 2008; Consedine et al., 2004; Consedine et al., 2006; Hay, Buckley, & Ostroff, 2005). In any case, some framework that helps justify the selection of these specific components and their separation would help the manuscript in general as well as in dealing with the general anxiety aspects which “hang” somewhat in the work.

We acknowledge the reviewer’s concern about the single item measures and we have now elaborated a bit more on this in the limitations paragraph in the Discussion. We also agree that the measures are not necessarily the best operationalisations of the construct. We have expressed more clearly in the manuscript that this is an exploratory analysis to examine the relationships between these items which do nonetheless seem to tap into three components of cancer fear. The
population-based sampling and the large sample size allow us to explore these issues, where exploring them in their own right might be unlikely, because they require large studies that may be unlikely to receive funding. We therefore feel that there is an obligation to use existing large datasets that may inform our understanding of cancer fear, and accept that the measures used in these studies may have been imperfect. We have edited the Background, Methods and Discussion sections to reflect these considerations.

We would like to thank the reviewer for bringing previous work that distinguishes among worry-like constructs to our attention. In fact, in earlier drafts of this paper, we had included this work, but took it out again for reasons of brevity. Based on the reviewer’s suggestions, we have now re-included a description of these issues in the discussion along with some of the suggested references.

3. Three, the rationale regarding possible links between demographics and the fear components is overstated insofar as it is not entirely accurate to suggest a complete absence of prior work testing whether demographic and psychosocial factors equally predict different aspects of fear. Several of the works noted above include multiple fear-type metrics and provide correlational analyses indicating the links between demographics and distinct components may vary (see e.g., Consedine, et al., 2008). Again, the obvious way to circumvent this problem is to note prior works in the area but then suggest that most prior work is US based (an assertion that is more consistent with the available evidence) and that such links may vary in UK samples.

We thank the reviewer for highlighting this. We have edited the Background of the manuscript so that it now better reflects the previous work that has been done in this area and included the suggested reference, as well as others.

4. Four, it is also worth noting that while anxiety is typically greater in women it is not consistently greater in minority groups and, in many US-based studies, anxiety, depression, and negative affect are actually lower. Thus, although it may be true that cancer worry is partially “driven” by general anxiety, these two phenomena are only moderately correlated (as the study itself indicates). My suggestion here is that the authors avoid trying to create a rationale to “explain” group-based differences in cancer worry/fear via general anxiety and position it more as a possible “nuisance” or confound-type variable that interferes with our ability to evaluate demographic predictors of variation in worry constructs rather than in anxiety per se. Such an approach would enable the manuscript to circumvent the complex literature dealing with anxiety in different groups.

We have addressed this comment by adding a sentence about the relationship between ethnicity and general anxiety to the Background. Following the suggestion of the reviewer, we have positioned general anxiety as a confounding variable.

5. With the exception of the validity concern mentioned above, the study is generally adequate at a methodological and analytic level. There are, however, a few areas in which greater detail would be
of use. Specifically, it would be useful for the reader to know a little more about the sampling strategy and rationale, the auspices under which persons were approached for participation, and the measurement context/content for the parent study (i.e., what else was measured). Similarly, I felt that a brief summary of the analytic approach, indicating which analyses were going to be used to deal with which research questions would help offer some greater structure to the Results section.

We have addressed these comments by adding more detail about the parent study and by adding which analyses were used to address which research question in the Methods and Results sections.

6. Finally, there are a few areas in the Discussion that should be addressed. In particular, greater care needs to be taken in suggesting that cancer worry may interfere with screening and/or promote delay. As the authors are like aware, this is a complex issue and not one that is addressed empirically in this work. While it is true that greater cancer worry may increase utilization, it likely also increases screening. Perhaps more to the point, there is little evidence that cancer worry per se deters either responses to symptoms or screening participation. In fact, the opposite is more typically the case. Recent theory (e.g., Consedine, et al., 2008) suggests that people normatively behave in a manner that reduces fear or worry but that the precise elicitor of the emotion is important when seeking to understand the “direction” of behavior. So while cancer worry tends to predict greater screening, fear of cancer may predict less, as may fear of screening or fear of finding something wrong. This interpretation needs to be changed as it misrepresents what is currently known about how cancer-related anxieties relate to screening behavior.

We thank the reviewer for highlighting this issue. We have changed parts of the Discussion section to better reflect what is currently known about the effect of cancer fear on behaviour.

7. One general consideration when reading the paper regards providing a reason for the reader to “care” about the epidemiology and predictors of cancer fear. Specifically, one of the key take home messages is that cancer is commonly feared in the UK context. Given, however, that cancer fear/worry is a robust predictor of greater screening (Consedine, Magai, Krivoshekova, Ryzewicz, & Neugut, 2004; Consedine, Morgenstern, Kudadjie-Gyamfi, Magai, & Neugut, 2006), this would not necessarily seem to be a major problem from a public health perspective. The Discussion mentions possible interference with QOL and it might be useful to bring something of this rationale into the Introduction.

We thank the reviewer for this useful comment and have now added to a paragraph about the study rationale to the Background section, and have added what the study adds to what is currently known to the Discussion section.
Reviewer 2 (Jennifer Hay)

1. While the topic of cancer worry and behavioral and psychological outcomes associated with cancer worries is an important issue in cancer prevention and control, it is unclear what this paper adds to the literature.

We thank the reviewer for highlighting this issue, which is similar to remarks made by Reviewer 1 (points 1 and 7 above). We have edited the Background and Discussion sections of the manuscript to describe more clearly what the paper adds to the current literature.

2. In terms of the demographic assessments, given the sample was almost exclusively (96%) White, the few individuals representing other ethnicities were merged together for the analyses, making it difficult to interpret the meaning of higher fear in the very small non-White group.

We agree with the reviewer that the non-White group is a small group which represents a number of different ethnicities and that combining these into a single ‘non-white’ group makes it difficult to interpret the meaning of high cancer fear by ethnicity. However, not including ethnicity seemed inappropriate, because earlier research has shown differences in cancer worry by ethnicity (e.g. Consedine et al., 2008; Consedine et al., 2004). The analyses in the paper explore whether there were any differences in cancer fear by ‘ethnic minority’ versus ‘ethnic majority status’, rather than by specific ethnicity. If we had wanted to explore differences in cancer fear by ethnic group the parent study would have needed to oversample among those of different ethnic minority backgrounds, which was not done in this population-based study. We acknowledge that this is a limitation and have included a statement in the Discussion section that this limitation makes it difficult to interpret our findings about ethnicity.

It should be noted that the small proportion of non-White ethnic background in our sample is consistent with the proportion of ethnic minorities at the time of data collection: data from the 2001 UK Census showed that 92% of the general population were White and only 8% belonged to various ethnic groups (Office for National Statistics, 2005). Non-White groups were also shown to be younger, i.e. the proportion of those of non-White ethnic background within the age range of our sample (55-64 years) can be expected to be lower than in the population as a whole. We have added this to the paper.

3. Further, the education question, “do you have any educational qualifications?” would seem to be open to wide interpretation by study participants, making it difficult to interpret this finding, as well.

We have now included the exact wording of this question in the Methods section and explained that this question assessed whether respondents had completed secondary education or not.
4. The strength of the study is certainly the large sample size, yet it is unclear whether this sample is representative of the general population or of those who attend primary care clinics.

We have addressed this comment by providing more details about the parent study and the recruitment process in the Methods section. We would like to note that almost everyone in the UK is registered with a General Practitioner. However, the exclusion criteria for the FS trial (which have been added to the Methods section) may mean that the sample is slightly healthier than the general population of the same age.

5. The weaknesses of the study involve the lack of clarity concerning the significance of the research questions, as well as whether the study provides any novel findings.

We have edited the Background and Discussion sections to explain more clearly why a deeper understanding of the construct of cancer fear is useful and what the current study adds to what is already known from previous studies.

6. Finally, the discussion section presents the rate of high cancer worry in the population (about one-quarter) in an exclusively negative light, which does not adequate capture the full implications - both good and bad - of cancer worries. While a quarter in this sample worried a lot about cancer, three-quarters did not worry much or at all...could this also be a bigger problem? Worry has been found to galvanize cancer screening such as mammography screening for breast cancer, as well as colorectal cancer screening, but this substantial literature is not discussed.

The Background and Discussion sections now state more clearly what is known about the behavioural effects of cancer fear and how the current paper adds to our current understanding of cancer fear by showing that it may be a multi-dimensional construct and that an understanding of its different components could help understand the different behavioural effects of cancer fear. We have added to the Discussion section that three-quarters of the population not worrying about cancer may also be seen as a problem.

Additional comments

Background

7. The significance of examining different aspects of worry and fear, whether they inter-correlate, and whether demographics correlate consistently with each type of worry is not made clear. Why does this warrant study? Would some aspects of worry promote behavior change whereas some aspects inhibit it? Would some forms of worry lead to distress and others not? A thorough literature review is needed here to provide a basis for the significance of the current questions and data used to assess it.
We notice the similarity between this comment and comments made by Reviewer 1 (e.g. points 1, 2 and 7). We have edited the Background and Discussion to explain the importance of the current study in terms of what it adds to our current understanding of cancer fear, its implications on quality of life, and its effect on behaviour.

8. The use of an older participant sample is neither discussed nor justified here. It could be argued that worries about cancer might be more or less salient in an older sample – what is the literature? Why does this sample warrant study?

To address this important issue, we have included a statement in the Discussion section that cancer fear has generally been found to be lower in older adults, but that we failed to find an effect of age in the current sample. We have explained why we were limited to this age group in the Methods section. We still feel it is important to study cancer fear in this sample as the participants are in the age for screening and at the beginning of an age-related increase in cancer risk.

Methods

9. It would be important to consider personal or family history of cancer in demographic variables.

We agree with the reviewer that these would have been important variables to consider. Unfortunately, the parent study only included data about personal and family history of bowel cancer, and we considered it inappropriate to use that as a proxy for personal or family history of all cancers. We have included the lack of personal or family history of cancer as a limitation of the study in the Discussion section.

10. Throughout the methods section (ex: line 103, line 106), dichotomization of variables in “some analyses” is described. This section and the recodes should be much more specifically and transparently presented, with rationale for recoding.

We have now added to the Methods section why certain variables were dichotomised and whether we used the dichotomised or undichotomised items for each analysis.

11. It is not clear that the measures available are adequate to answer the proposed questions. For cancer fear, three specific items are used, and while they appear face valid, they are extracted from an established measure. Why wasn’t the full measure used, where reliability and validity data could be cited? How do these items relate to established measures for cancer worry, or intrusive ideation about cancer? It is unclear, then, what the moderate correlations between the items represent, as the three unique items used to assess the proposed three different elements of worry may or may not adequately represent these three elements.
We notice the similarity between this comment and comments made by Reviewer 1 (see point 2 above). We have tried to address these comments by adding more detail about the established measure in the Methods section and by explaining why we have chosen to use only these items as measures of cancer worry for the current study. Other authors have previously used this established measure (or some of its items) as a measure of cancer fear to assess the effect of cancer fear on cancer screening uptake (e.g. Consedine et al., Preventive Medicine, 2004; Miller & Hailey, Womens Health Issues, 1994).

The original Cancer Attitude Inventory includes various domains of cancer attitudes (e.g. stigma, economic hardship, potential for personal growth), but the scale has not been divided into subscales to represent these different domains. The items for the current study were therefore chosen for their face validity. One of the items used in the current study (‘I often worry about cancer’) is commonly used as single item measure of cancer worry, for example, in the US Health and National Trends Surveys (HINTS), and another item (‘Of all the diseases there are, I am most afraid of cancer’) is similar to what is reported in the population surveys described in the introduction of the paper.

We agree with the reviewer that the chosen items may not adequately represent the three cancer fear elements and we have acknowledged the limitation of the single item measures in the Discussion section (see also response to Reviewer 1, point 2).

Statistical analyses

12. It would be useful here to clarify the dependent variables used. The section describes the two multivariable logistic regressions, which are called “model 1” and “model 2” in Table 3. Please provide a description of “models 1 and 2” in Table 3. Please provide the terms model 1 and model 2 in the statistical analysis section.

We have included a more detailed description of the models and the dependent variables in the Methods section. We have also provided a description of the models in Table 3.

Results

13. 63% reported no “educational qualifications”? What does this mean? No primary school? No university?

This item assessed whether participants had completed (at least) secondary education or not, as we have now explained more clearly in the Methods section.

14. The questionnaire return rate is not high at 60%. Were participants aware that the survey involved cancer? Non-responders could have been more worried about cancer than responders; are reasons for refusal available for reporting?
Yes, participants were aware that the survey involved cancer and we have clarified this by adding more detail about the parent study in the Methods section, and have mentioned this as a limitation in the Discussion.

Unfortunately, no reasons for refusal are available for reporting, and thus we cannot rule out that there was an effect of cancer fear on questionnaire return.

As the reviewer points out, the response rate of 60% is not ideal, but even the Office for National Statistics (ONS) Omnibus Survey, which uses face-to-face interviews and is generally considered the ‘gold-standard’ of surveys in the UK, is currently only achieving a response rate of about 60% (ONS, 2014).

Since the age range was narrow, and most participants were married, it is not surprising that age and marital status were not related to fear indicators.

Actually, there were 1,650 participants who were not married, so this is a pretty large number, but we have included the age limitation in the Discussion.