Author’s response to reviews

Title: Prostate-Specific Antigen (PSA) and distress: - a cross-sectional nationwide survey in men with prostate cancer in Sweden

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Author’s response to reviews:

Dear Dr. El-Hajj!

Thank you for the positive response, review, and valuable suggestions of our manuscript “Prostate-Specific Antigen (PSA) and distress: - a cross-sectional nationwide survey in men with prostate cancer in Sweden” (BURO-D-19-00038) and for considering it for publication in BMC Urology. We hereby submit a revised version of the manuscript where all comments from the reviewers have been taken into consideration. Below you find our responses to the comments point by point. We have also made small corrections in the tables adding units to variables. These changes do not in any way change the content of the results.

Looking forward to hearing from you again.

Yours sincerely

Ulrika Rönningås, RN, MSc, Corresponding author

Reviewer 1

Title- The study title should include the study method and the study population and the country where the study was done.

Thank you, the title has been changed according to your suggestion. (Title page)
Abstract- The division into PSA subgroups should be in the methods not the results.

Thank you for this comment this has been changed accordingly. (Last sentence, methods section abstract)

The results section of the abstract is not clear it should be summarised more and only the key positive results given

The result section in the abstract have been shortened and more focused on key results.

1. The questionnaire were sent to the participants and therefore self administered, this weakens the data obtained

We agree in that there are limitations in self-reported data but outcomes such as distress and Quality of Life are subjective measures and are most useful to measure with self-administered questionnaires. As was stated in the strengths and limitations section (p.6, line 26-28) we also believe that it would have been valuable to confirm the medical data but unfortunately it was not possible in this nationwide sample with anonymous answers.

2. No key informant interviews or focus group discussions were done to re-enforce the results from the questionnaire

This could have been a good way to re-enforce the results. This was however not the focus of this study but may be interesting for further studies.

3. There was selection bias, in selecting only the clients who responded, these are mostly likely to have had distress with PSA levels (55% of the total 6,389)

We agree on that this may be a selected group in some sense due to that all included men are members from the Swedish Prostate Cancer Federation, as also discussed under strengths and limitations. However, the 55% response rate is based on the fact that the questionnaire was sent out to all members of the federation, also consisting of family members/relatives, professionals as well as individuals who join the federation in support of it. Unfortunately, the federation do not have information on how many of the members that are patients. This means that among the 45% who did not respond to the questionnaire, a large proportion may not have been patients. As stated in the Strengths and Limitation section (p.6, line 10-19 new sentences line 15-19) previous studies on members of the SPCF have however shown that that men often do not join patient associations due to distress or, as for women, due to psychosocial needs related to having cancer. For men with Prostate cancer the motives are rather that they want the information and activities the associations could provide which may not support the assumption that these men would be more distressed than other men with Prostate Cancer.
4. The group of PSA results was too wide 0-19ug/l the normal PSA 0-4ug/l so a group of 0-4, 5-10, 11-19, >20 would be expected. Anyone with a PSA >5 is likely to be distressed

Thank you, this may be a relevant suggestion. However, we believe that the grouping suggested is more relevant before the prostate cancer diagnosis or in relation to curative treatment when small variations in PSA are more significant. The men in the present study are diagnosed with prostate cancer in different phases, from cured to palliative and the aim was to illustrate the impact of the higher PSA-values and therefore the groupings suggested by Koo. et al. (2015) were used.

5. The common measure of PSA is ng/ml the use of ug/l maybe confusing to most readers

Thank you for this suggestion, we have changed the measure to ng/ml throughout the manuscript to better fit an international audience (Abstract, p.3, line 2-3, 27-28, 33, 40-41 p.4, line 9-10, 25)

6. The question designed to measure distress was too weak and the response quiet imprecise. since this was the major outcome variable a quantitative measure with several questions is required here.

We agree that the question may have been imprecise, but we believe that it is also a strength since the question covers many aspects of distress which is also discussed in the strength and limitations section (p.6, line 20-25).

7. There is an overlap between quality of life score and distress, since they both measure patients discomfort it seems the QoL score includes distress so the two cannot be compared

We are aware of that there may be an overlap between these concepts. But since we wanted to use some kind of measure on overall health we decided to include QoL but in a separate model. This is also discussed in the discussion section (p.5, line 20-33).

8. The men older 73 will most likely have a higher PSA and higher distress by virtue of age alone. The study dichotomized men into two group as <74 and 74 and older

Earlier studies have shown associations between distress and younger age as stated in the background and discussion section (p.1, line 44, p.2, line 1-3, p.5, line 34-41) so that was the reason why we adjusted for age in the multivariable analyses. In this study age did however not show an association.
9. The study compares too many variables without selecting out from the literature review the most important elements to be considered.

In the background literature review, we report results from studies showing associations between distress and social factors such as age, but also hormonal treatment. As stated above, QoL was involved as a measure of overall health. Both level of education and civil status may be related to the possibility of having support if distressed and were therefore included. The association between distress and living alone is also discussed in the results section from this angle. In relation to the large sample size we do also consider this a reasonable number of variables.

The descriptive data should be presented first before the analytical data.

The descriptive data are presented in Table 1 and the results from the bivariate and multivariable analyses are presented in Table 2; hence we do not really understand the content of this comment.

Reviewer 2

For practicing clinicians, it would be very useful if any measures or suggestions can be implemented to decrease the overall impact of distress that is caused by waiting for investigation results, especially PSA. Any practical tips in dialogue with the patient or clinical practice can be proposed in the discussion section.

Thank you, we have added a section about clinical implications of this study in the discussion section (page 5, line 42-44, p.6, line 1-2).

Reviewer 3

Topic of intermediate clinical relevance, article well written.

Thank you for this comment!