Author’s response to reviews

Title: Self Evaluation of Communication Experiences after Laryngeal Cancer - Longitudinal questionnaire study in patients with laryngeal cancer.

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Author's response to reviews: see over
We would like to express our gratitude to the reviewers, the comments and suggestions were very valuable to us and, in our opinion, helped improve the paper. We also appreciate the time spent on this manuscript. Below we have replied on each comment.

Reviewer 1 - General

Minor Essential Revisions (such as missing labels on figures, or the wrong use of a term, which the author can be trusted to correct) This paper describes a very well conducted study on the Swedish version of the SECEL questionnaire, which is now applied in a prospective longitudinal survey in a large cohort of patients with laryngeal cancer. The outcomes of the study are convincing and the conclusion that this questionnaire is a more suitable instrument than the more general EORTC questionnaires is valid. The paper is well written and almost flawless. My only remark is that I have no clue what “a battery of PRO questionnaires” is (page 7 first line of the Design paragraph. If this is explained by given the meaning of the abbreviation, this problem probably is sufficiently solved. Furthermore, I would add in the appendix the 4 answer categories for questions 1-34 and the 3 answer categories for question 35. These categories are mentioned in the text, but for clarity it would be easier to also add these to this appendix. Both corrections/additions are so minor that they can be made by the authors without any further revision in my view. In conclusion, in my opinion this is a very valuable paper about a well conducted and relevant study, well worth to be published in BMC Cancer.

PRO stands for Patient reported Outcomes, has been added to the text.

Reviewer 2 - General

The topic is interesting and worthwhile to publish. However, my main concern is: Why did you exclude patients with poor general health? As a consequence you have only 5 laryngectomees in your study - and they should have the most speech problems of all laryngeal cancer patients.

Only the patients unable to participate due to heavy disease burden were excluded. It is true that a larger part of the excluded patients were laryngectomised, which is natural since they more frequently had a more advanced stage of disease, and hence had to undergo laryngectomy. That the excluded patients had a more advanced disease is mentioned as a shortcoming in Discussion.

Another point you seem to mix up when you compare SECEL and H&N35 (by the way - both of them are equally long, namely 35 items).

The originators of the H&N35 never intended the H&N35 to be used on its own, it was developed and psychometrically tested as a tool to be used in combination with C3, which adds up to 65 items.

You state that the SECEL is shorter AND more precise. This may be true for the speech rehabilitation issues. However, the EORTC QLQs are intended to measure quality of life in different domains, speech is only one of them. I think you should consider that in your conclusions.

The aim of this study was to find a questionnaire that is suitable to evaluate Communication Experiences, and for that the SECEL is more precise. This has been made more clear in Conclusions.

Major Compulsory Revisions: Abstract:

- You claim that you have conducted “the largest longitudinal study concerning HRQL in laryngeal cancer patients”. This is not true. In 1978 Warnecka-Przybylska and colleagues
already investigated 133 patients with laryngeal cancer prospectively regarding their mental and social well-being (Warnecka-Przybylska 1978). In 1984 Berger and Heilmann published longitudinal quality of life data from 253 laryngectomees (Berger und Heilmann 1984), in 1990 Laptchenko et al. reported about 140 laryngeal cancer patients (Laptchenko et al. 1990), in 1992 de Maddalena et al. gave information about 74 surgically treated laryngeal cancer patient (de Maddalena et al. 1992). Ramírez et al. investigated 62 patients with the PAIS-SR (Ramírez et al. 2003). It is true, these papers were not published in English, but in Polish, German, Russian, and Spanish, and therefore it would need some effort to translate them. However, all of those were published and it is not correct to say that there have been no larger prospective studies regarding HRQL in laryngeal cancer patients to date. Even if you would consider only English papers — there are studies with 92 (Ward et al. 2003) and 107 (Weymuller et al. 2000) study participants which have been published in English.

This is a mistake from our part. During the re-writing of the paper the word “Scandinavian” went missing. We have now revised the text to “largest Scandinavian study”.

Materials and methods: Who did assess psychiatric health and how?

**Patients excluded due to dementia or other psychiatric disease had been diagnosed earlier by a psychiatrist or GP.**

Results:
- Please report effect sizes and p-values also for the EORTC QLQs (in table or text)

**Has been added.**

Report of the HADS cut-off prevalence seems not necessary in this paper

*We do not agree since the prevalence of possible/probable anxiety and depression is not transparent from mean values alone.*

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Minor Essential Revisions:

Abstract: - first line: I assume you mean "sensitivity to change"

**Has been changed.**

- The number of n=100 patients is misleading, your study was conducted with 76 patients, as I understood.

**No, the study was conducted with 100 patients, but with gradual drop-out 71 remained at the endpoint. This is explained clearly in results.**

- Please insert the exact numbers, instead of just saying "high response rate" or "statistically significant".

**Done.**

- You should explain your abbreviation HRQL at the first mention.

**Done.**

- What do you mean with "more suitable" - suitable for what?

**For communication experiences, has been added.**

- What do you mean with "on an individual basis"? To my knowledge, this is also possible with the EORTC QLQs.

**To our knowledge the EORTC QLQs were developed for use on group level.**

Your conclusion regarding planning of treatment is not supported by your data.

**Has been changed to “help plan rehabilitation”.**
Introduction: - Line 4: 
To my knowledge, the study of Mohide et al. (reference [1]) did not investigate psychiatric morbidity, you could better find another reference for that statement. 
*Has been changed.*

Materials and methods: 
- Please differentiate between decline because of mental vs. physical health. 
The 17 patients that declined participation did not have to state the reason for declining, for ethical reasons. 
- The reasons for exclusion sum up to 107, but you had excluded 110 persons. 
*This has been corrected; three patients were excluded because of other concurrent cancer diagnosis had been left out.*
- Please explain PRO at the first use. I assume that it is Patient Related Outcome, but not everybody would know this. 
*Done.*
- Please report numbers of drop out with each measurement point. 
*Done.*
- page 6: I would suggest to reduce information about radiotherapy, this is not important for your study and you do not use this information later on in the manuscript. 
*Done.*
- You should better describe the treatment of your actual sample, not of the 100 patients you had at the beginning. 
*Since this is a longitudinal study, the focus is not on endpoint solely. Therefore we find it relevant to describe the treatment of all included patients.*
- page 8, line 7: the word "scale" is missing 
*Done.*
- page 8, line 8: the ";" should be removed 
*Done.*

Results:- line 3: please add "of disease" to "stage" 
*Done.*
- isn't there a contradictoriness bewtween line 3 and line 6 regarding the effect of stage of disease? 
*Has been corrected.*
- data not shown: ... but this would be interesting to read 
*Including this information would result in too many tables.*
- please report response rate at every measurement point 
*Done.*
- page 10, line 2: active disease AND dead? I think you mean OR 
*Has been corrected.*
- please explain "items response rate" 
*Done.*
Discussion
- page 13, line 3 and 4: seems not logical, please explain better
Has been elucidated.

Table 2
- please report to which measurement point the p-values refer
Has been added.

Discretionary Revisions (which the author can choose to ignore)
Materials and methods:
- page 5, last two lines: You doubled "smoking habits"
Has been corrected.

- page 8: Statistical methods and ethical aspects should be handled in different Chapters
Has been changed.