Author’s response to reviews

Title: Experiences of positive encounters with healthcare professionals among women on long-term sickness absence due to breast cancer or due to other diagnoses: A nationwide survey

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Author’s response to reviews:

Regarding manuscript PUBH-D-18-00354

Dear Editor,

We are very grateful for the possibility to resubmit a revised version of our manuscript “Experiences of positive encounters with healthcare professionals among women on long-term sickness absence due to breast cancer or due to other diagnoses: A survey” (PUBH-D-18-00354). We are also grateful for the useful comments from the reviewers and have handled the comments in the revised manuscript according to the suggestions by using “track change” for the manuscript. Thank you also for the late arrived comments from one reviewer, comments regarding the first version of the manuscript - we have responded to those as well.

Based on those comments we also revised the title to: “Experiences of positive encounters with healthcare professionals among women on long-term sickness absence due to breast cancer or due to other diagnoses: A nationwide survey”. Moreover, the language is checked and references updated.

Please find our responses to reviewer comments below, also indicating lines where information has been added, when applicable.
On behalf of all the co-authors
Mirkka Söderman
RN, MsN, PhD student,

Comments and responses on Revision 1 version

Reviewer 1, Rose Maly, MD, MSPH: no further comments

Reviewer 2, Miyako Takahashi, M.D., Ph.D.

Reviewer comment: The manuscript have been somewhat improved according to the reviewers' suggestions. However, I still doubt the comparability between BC groups and other groups.

Response: Thank you for this comment. Of course, one could use this large data set for many different types of comparisons. However, our main focus in this study was experiences among long-term sickness absent women diagnosed with BC. We also wanted to gain knowledge of whether their experiences differed from those of other long-term sickness absent women irrespective of sick-leave diagnoses. We are not sure what you mean with ‘comparability’ here. Of course the other women had other diagnoses that led to them having been assessed as having such long-term work incapacity. They are comparable in terms of being women of working ages, of having been on sickness absence for many months – differences between the two groups in terms of age, birth country, and other sociodemographics were statistically handled through statistical adjustments. Most long-term sickness absences are, in Sweden as in other OECD countries, due to mental or musculoskeletal diagnoses. Other studies, with other focus could of course use other comparison groups – e.g., people with other cancer diagnoses, people with CVD or injury diagnosis, etc. Comparisons could also be done with men.

Thus, in this explorative study, the focus was on women with BC, a group large enough in our data to be studied and compared with women with other sickness absence diagnoses.
Reviewer comment: Although the authors state that the main reason of sickness absence among BC group is side effects of treatments not the cancer symptoms, it can apply to other types of early-stage cancer.

Response: You are right. Also, as we here have no information about when during the BC trajectory the now ongoing sickness absence spell begun, for clarity we excluded this sentence in the revised manuscript.

Reviewer comment: Also, the age distribution and the depressive symptoms are significantly different.

Response: It is correct that both the age distribution and rate of participants with depressive symptoms are significantly different between the two studied groups. Therefore, we presented both crude results and results adjusted for these factors in the statistical analysis – as is commonly done in these types of analyses to handle such differences. We, of course, also wanted to know if the small differences in encounters were associated with such differences between the groups.

Reviewer comment: The authors could have focused on the data of BC patients only, or they could have compared all types of cancer patients with non-cancer patients. Because this comparability issue is too big to be considered as limitation, I advise the authors to re-analysis the data.

Response: Based on your suggestion, we conducted sensitivity analyses, comparing the BC group with the group of women with all other SA diagnoses excluding those with any SA cancer diagnoses. The estimates (odds ratios and confidence intervals) for the experience of any positive or negative encounter did not change. We also observed that the group of women with other cancer diagnosis was more alike the group on SA due to all other diagnoses than the group with BC, except regarding age; they were older. Only 3.6% of the women were on SA due to other cancer diagnoses. We have now added information about these sensitivity analyses in the revised manuscript (see page 6 lines 22-24 and page 7 lines 9-11). The aim of this study was to compare experiences of women with BC to that of all other women on long-term sickness absence. We are, in this explorative study, foremost interested in the experiences of women with BC, in order to get bases for interventions. Actually, we first considered, as you suggest, to only include
women with BC. However, we decided to expand the analyses and compare their answers with those of all other women on long-term sickness absence, to see if there were any differences at all.

Reviewer comment: The paper also needs language corrections.

Response: We have now conducted a thorough language revision, and made changes accordingly.

Reviewer 3 Ariane Leroyer: no further comments

Further comments and responses on original version

Response to the editor: Thank you for providing also these comments! Actually, they do not differ much from the comments from the other reviewers regarding the first version of the manuscript. Thus, we have already answered and clarified most raised issues in our previous revision and response letter. However, we have now also responded to these comments see below.

Reviewer 4: comments on the original version submitted

Reviewer comment: Long term sickness absence among BC patients is a relevant topic. The questionnaires were sent to a large population of sickness absent individuals in Sweden in April 2013. The results are outdated. This is a general survey and was not specifically designed to capture the views of cancer patients. This study does not provide useful insights and the conclusions are not strong enough.

Reviewer comment 1: The survey is outdated (>5 years), and the questions included in the survey are too unspecific to draw evidence-based conclusions.
Response: This is a study of how a very large number of women on long-term sickness absence (N=6197) experienced encounters with healthcare professionals in 2013. There are no indications that how patients experience different types of encounters (e.g., being treated with respect, being listened to, answered my questions, etc.) would become irrelevant or outdated over the years. On the contrary, such encounters are now stressed even more in healthcare organizations in many countries, emphasizing patient-centeredness of the encounters with patients.

The questionnaire was previously, in 2004, used in a large nationwide survey (about 5800 participated of the about 10,000 invited). Moreover, most of the survey items regarding different types of encounters have been included in other, smaller, questionnaire surveys both before and after the large one in 2013 used in the submitted paper (N=17,400 women and men invited). When comparing the results from 2004 with those from 2013 there are only very small differences concerning long-term sickness absentees’ experiences of encounters with healthcare professionals. This, in spite of differences regarding guidelines/recommendations for sickness certification, regarding treatments, etcetera.

As you point out, this is a general survey, which we see as a major strength of the study. Participants received the same type of questions irrespective of sickness absence diagnosis, work situation, age, sex, etcetera. Otherwise it would not have been possible to compare results between different groups.

Evidence-based conclusions should be drawn from systematic literature reviews and not be based on single studies. Hopefully, in the future this exploratory study may be included in such reviews and thus add to evidence.

We agree that some of the questions, as they were expressed in the original submitted version, seemed too unspecific. We, based on the previous comments from the other reviewers, realized that our translation of some of the items into English from the Swedish questionnaire made them seem more abstract or unspecific than what they actually were. The items had been shortened to fit the tables – this was a mistake. We have since then revised and also rephrased some of the items so that they better match the actual phrasing used in the Swedish language questionnaire.

Reviewer comment 2: The authors sent a questionnaire by mail in April 2013, containing questions such as:
Did you experience a positive encounter with someone in health care during sick leave?

Did you experience a negative encounter with someone in health care during sick leave?

Every patient has its own definition of a positive/negative encounter.

Response: We agree – and it actually is that definition/experience of the individual patient that we are interested in. That is the reason why we ask both about the sickness absentees’ experiences of the encounters in general, as well as about having experienced more specific situations/encounters. We are in this study interested in how each of the women experienced their encounter with the healthcare professional. How the patient herself experiences such encounter is our focus here – as it is based on that experience the patient reacts and acts. Not on what ‘objectively’ happened during the consultation.

Thus, if the patient herself experienced (or ‘defined’ using your wording) the encounter as positive or negative was one of our focuses in this study. In the questionnaire we also gave about 20 examples of positive and negative encounters, respectively, to indicate what could be included as such – all based on previous studies of patients experiences and statements about what encounters might affect RTW.

Reviewer comment 3: "someone in health care" is not specific enough to determine which medical professional is involved.

Response: In this study the aim was to capture experiences of encounters from healthcare professionals as a whole since this has been shown to be important for RTW among sickness absentees in previous studies. Thus, our main interest was not with what type of healthcare professional they had had the encounter. Nevertheless, as stated in the manuscript, there also was a specific question about with which one of eight different healthcare professions the participant had the respective encounter. Further, in another question, we also asked if the encounters from specific groups of professionals had been mostly positive or mostly negative. Regarding all types of professionals that the sickness absentees had had interaction with, a majority of them responded that those encounters had been positive (see manuscript section “Encounters with different healthcare professions”).
Reviewer comment 4: Unfortunately, the statements in table 2 are also unspecific and there is a lack of relevant information.

Response: Please note that the items in Table 2 have been rephrased and clarified regarding this since the original submission. In our first submitted manuscript the items were shortened to fit the tables – this was a mistake. We have revised and also rephrased some of the items so that they better match the actual phrasing used in the Swedish language questionnaire.

All the survey items are based on previous studies (individual and focus-groups interviews and questionnaires) about what sickness absentees found affecting their RTW – in general and as well as regarding encounters with healthcare and others. Of course many other aspects at different structural levels might affect RTW – however, in this study our focus was specifically on experiences of encounters with healthcare professionals, as experiences of encounters with healthcare have previously been found to affect RTW. We hope that the results can be used as bases for both interventions and for studies based on other data including also other type of information.

Reviewer comment 5: The statements in table 2 lack further explanation. For instance, the statement "believed in my work capacity" is not relevant because the evaluation of work capacity is not a task of nurses or treating physicians of cancer patients. Evaluation of work capacity is the task of occupational health physicians or medical advisors. These professionals were not mentioned in this study.

How can a nurse or a physiotherapist believe in the work capacity of a patient?

Response: The item "believed in my work capacity" was one of the items that were rephrased to better correspond to the actual item in Swedish that was used. It is now phrased into “believed in my capacity to work”, capturing the sickness absentees’ experience of being believed regarding her capacity to work. In previous studies, that has been shown to be an important aspect among sickness absentees regardless of which profession they have been encountered by.

This item is not related to the healthcare professional’s actual clinical assessment of the work capacity in relation to sickness absence benefits. But more in general capturing being considered to have some work capacity – e.g., during rehabilitation measures, when being considered for such measures, or when talking to for example a nurse about the future.
Moreover, in Sweden, in contrast to some countries, the sickness certificate necessary for the patient’s claim of sickness absence benefits is written by the treating physician, e.g. by a GP or by an oncologist (sometimes the physician asks also for an evaluation by a physiotherapist or occupational therapist). Thereafter, it is an officer at the Social Insurance Agency who decides if the patient fulfills the criteria for sickness absence benefits (if unsure the officer can consult a medical advisor, however, the later never sees the patient).

Reviewer comment 6: The statement "believed me" (believed what?) This statement lacks explanation. Each patient can understand something else when reading this statement.

Response: You are right and we have rephrased this and some other items so that they are in line with the wording in the Swedish questionnaire. It now reads: “believed what I said”. This is in most previous studies about experienced encounters found to be an essential aspect, whether the patient experience that the healthcare professional believes in what he/she states or not, e.g., about their symptoms or situation.

Reviewer comment 7: This survey took place more than 5 years ago; I do not understand why it took so long time to publish these results. The last years many relevant studies have been published about this topic.

Response: There are no indications that how patients experience different types of encounters (e.g., being treated with respect, being listened to, answered my questions, etc.) have changed much over the years, and such encounters are now stressed even more in healthcare organizations in many countries, emphasizing patient-centeredness in the encounters with patients.

Our aim was to gain more knowledge on how long-term sickness absent women with BC experienced encounters with healthcare professionals and if this differed to the experiences among women long-term sickness absent due to other diagnoses. Sometimes it takes longer time than expected to get funding and experienced researchers for specific studies, however, we do not see it as an issue that the data was collected some years ago. We have no hypothesis regarding that how patients experience different types of encounters from healthcare professionals will differ in any essential way over time, nor any indication regarding that the experiences do differ over time, comparing results from this survey with those from previous
large and small studies of this type. In general, the answers regarding encounters are very similar in this and another similar nationwide study conducted in Sweden in 2004.

Regarding recently published relevant studies, to the best of our knowledge, there are no other studies published the last years concerning encounters among sickness absentees in general except for those mentioned in our manuscript, and very few studies on encounters among women on SA for BC. Those we have knowledge of are Arfi et al (2018), Bondesson et al (20), Braybrooke et al (2015), Nilsson et al (2011), Tamminga et al (2012), and Söderman et al (2018) however, these all focused on encounters within the group of women on SA due to BC and did not compare the experiences with those of other women on SA, which was an aim in the current study.

Reviewer comment: 7. To sum it up, the conclusions in this study are not based on solid results.

Response: Thank you for this comment, we agree that one of the sentences in the conclusion did overstate the results, the conclusion have now been revised (See page 15 lines 5-21).

However, all results are based on the, to the best of our knowledge, largest (also internationally) survey of how long-term sickness absentees experience their encounters with healthcare professionals. The conclusions are based only on the results that were statistically significant, and/or adjusted for potential confounders. The response rate was, as discussed, a possible limitation (55.4%) – however, considering that the comprehensive questionnaire only was available in Swedish (many of the long-term sickness absentees are immigrants or not always capable of reading), and many were very ill, we consider the response rate acceptable. Also, that we have answers from more than 6000 women is in itself a strength of the study. Another is that over 20 specific types of encounters were included, providing knowledge at a very detailed level, as bases for interventions.