Author's response to reviews

Title: Associations between successful palliative cancer pathways and community nurse involvement

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Author's response to reviews: see over
Concerning MS: 1768922933258041
Associations between successful palliative cancer pathways and community nurse involvement

Dear Editor and referees

We thank you for your very useful comments and suggestions to improve our manuscript. We have rewritten the manuscript and have carefully taken all the comments into consideration.

Below are our comments to the referees’ comments. Our comments are written in red.

We look forward hearing from you again.

On behalf of the authors,
Yours Sincerely

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Reviewer 1:

Discretionary Revisions
The clarity and readability of this manuscript would be improved by having an editor perform basic “clean-up” of the language.
A language check has been performed

Methods
• Why were GPs compensated, but not CNs or relatives of deceased patients?
We would have preferred no compensation at all, but since the GPs are, in a way, employed on piecework in Denmark we considered this was necessary to get any response from the GPs. This is now explained in the last paragraph on page 6.

• Restructure slightly so that you have one paragraph per questionnaire.
Currently, text in paragraph one (beginning ‘The 46-item CN questionnaire…’) should be the start of a second paragraph on the CN questionnaire, and redundancies with the current paragraph two should be removed.
The paragraph ‘Data collection’ has been reconstructed. Iterations have been ‘cleaned up’ and there is now one paragraph per questionnaire.

• Text regarding the questions posed to relatives is repeated twice (“very well, well, fairly well, bad, very bad”); this redundancy can be removed.
This has been corrected.

Minor Essential Revisions
Abstract: The wording would be clearer if the authors stated that the aim was to examine associations between two factors – CN involvement and place of death – and bereaved relatives’ evaluation of palliative pathways.
This has now been clarified.

Methods
• Under Data collection, begin with a leading sentence that explains that data collection for this study consisted of three questionnaires, and state what they were.
This has been corrected.

• How were the questionnaires delivered – by mail? By personal delivery to the patient’s home? In a clinic or other health system setting?
This has been added in the first paragraph of ‘Data collection’.

• The statistical plan is well described.

Discussion
There is a missing word in paragraph seven of the Discussion: “We also found that dying at a nursing home was associated with relatives’ positive evaluation…”
We deliberately use “dying” as a (verbal) noun. Verbal nouns are nouns that are morphologically related to a verb and similar to verb in meaning; in English, this might be a gerund (ending in –ing like dying, eating, sleeping etc), an infinitive (to die, to eat, to sleep,
etc) or other noun derived from a verb. “dying” is grammatically perfectly correct and verbal nouns are used in many other places in the manuscript

Major Compulsory Revisions

Abstract:
• While a primary focus of the study is presented as possible association between CN involvement and bereaved relatives’ evaluation of palliative pathways, the Results section of the abstract does not report on this aim. The sentence “No significant associations were identified between the evaluations of the palliative pathway and how the CNs were involved and the degree to which they were involved.” should be moved to Results.
This has been done

• In the abstract Conclusions, the authors could comment on the significance of their findings with respect to CN involvement.
This has been added

Background:
• A more well-developed background section would provide better context for the study, support its rationale, and underscore the significant of results.
We have rewritten the background section and it is no more logically organised. However, there are different writing-styles when writing a background section for a paper, and we do not believe that one is more correct than the other. However, for this study we believe that the background should be clear-cut and we believe that the short, clear introduction still sets the scene, shows the lack of literature about this specific subject and demonstrate the need to do this study...

What proportion of terminally ill cancer patients and relatives desire a home death? Does this differ across national lines, e.g., in Danish vs. Dutch, American, or other populations? What proportion of patients wishing to die at home actually do die at home, vs. in nursing homes, hospitals, or other institutions? Have these proportions changed over time, and are there meaningful trends? Provide data and mention specific studies, rather than making general statements with a string of references.
We did not provide the above suggestions in the background since it did not come naturally in the background section to do so. (See also comment above) However, if you think this is crucial to publish the article – please let us know.

Similarly, provide some background on CN involvement – in what proportion of end-of-life cases are they involved? Is this model unique to Denmark or used in other countries as well?
This issue is also described in the setting – section. We, however, included some information about CNs as frontline workers in the patient’s home.

Studies are referenced which found that CN involvement impacts place of death. This is a key link, if place of death is associated with positive palliative pathway. Provide the basic data from these studies to illustrate strength of association, e.g.
We did not provide the above suggestions in the background since it did not come naturally in the background section to do so. However, if you think this is crucial to publish the article – please let us know.
• The first and third sentences in paragraph two appear to contradict one another. The basic point seems to be that CN involvement impacts relatives’ evaluation of palliative pathways (sentence 1), and that the association between CN involvement and evaluation of palliative pathway is unknown (sentence 3). The link appears to be the association between CN involvement and home death, but this logic needs to be better spelled out.

This paragraph has been rewritten. We hope it is now clearer. Previous studies have looked at the overall involvement of CNs, but not on different factors regarding the CNs and their services.

Methods

The principal issue with this manuscript lies in circularity in definition of terms. A “successful palliative pathway” was defined as one in which the dying patient’s home-based period was “very well” or “well” aligned with the way it should have been. At the same time, associations were sought between a successful palliative pathway and home death. By definition of terms, then, the study design will push toward an equation of home death with a successful palliative pathway.

This is now mentioned and discussed in the discussion section in the first paragraph of ‘Comparison with existing literature’

• In the beginning overview paragraph, explain that this was a cross-sectional questionnaire-based survey study that collected information from three groups: GPs, CNs, and relatives of deceased patients. (The abstract concisely does this.)

This has been corrected

State that a GP survey was used to obtain the patient sample (reference Figure 1), and then proceed with current text.

The GP-questionnaires were used to more than that (Which is explained later on in the article), so this is not corrected.

• “Successful palliative pathway” seems to be defined as the relatives’ comparison of the actual home dying period vs. how the home dying period should have been. How does this wording pertain to patients who died in the nursing home or hospital?

It appears from the article that all patients included spend time at home (otherwise they would not have a community nurse involved...) So, we believe that this wording is the same to all relatives. If you want us to write this clearer in the article, please let us know.

• In the Analysis section, clarify wording: A “successful” palliative pathway – as defined by the relative respondent on the questionnaire – was considered the primary outcome measure. Associations between successful palliative pathway and (1) place of death, and (2) CN involvement were calculated.

These phrases have now been corrected according to the above.

• I suggest that you have a statistician review the analytic plan; it is possible that there are too many factors included in the model relative to the sample size. A rough rule is that a ratio of 1:10 (factors:participants) should not be exceeded.

See comments to reviewer 3.
• The model is only briefly mentioned – is it truly a model, or rather a list of factors considered? Further description of the model you created, the variables it included, and how it was used would strengthen the narrative. Although Table 3 presents information on variables, the model itself belongs in the text as well, though without repeating the ratios presented in the table.

The model is now further described in the analysis section.

Discussion

• This is an interesting study in the Danish context. Could you briefly discuss how the Danish health care system parameters with respect to palliative/end-of-life care (nicely presented under Methods, Setting) compare with those of other countries’ health care systems? This could be used as the basis for discussing generalizability of your study’s findings.

We added a paragraph on generalizability: Now 3rd paragraph in ‘Strengths and limitations of the study’

• The lack of association of most model inputs with positive palliative pathway is striking – especially in contrast to place of death. This result could be highlighted and implications further discussed.

A paragraph about this subject is added at the end of the section: ‘Discussion of results and comparison with existing literature’

• In one quarter of cases with a CN response, the CN or GP advised against sending the relative a questionnaire. The authors note the possibility of selection bias in exclusion of cases where the CN did not know the patient well, or was less involved with the patient. Perhaps also the CN or GP was more likely to advise against sending the questionnaire in cases where there was involvement, but the palliative pathway was unsuccessful?

We believe that we have already described this bias (at the end of 2nd paragraph of the section ‘Strengths and limitations of the study’: ‘This would also be the case if the CNs or the GPs had excluded cases that they knew had been unsuccessful (which they might have chosen to do for a number of reasons) despite CN involvement.’

• How were model inputs selected? The discussion notes that symptom severity was not included. What was the rationale for this choice? Symptom severity would seem to be an important factor that may itself be correlated with relatives’ evaluation of the palliative pathway.

We included no variables that could describe symptom and problem severity since the included variables were identified through literature studies, clinical experience and group interview studies and this issue didn’t come up. This explanation has been added in 2nd paragraph of the section ‘Discussion of results and comparison with existing literature’

• It is interesting that studies have found CN involvement to be associated with bereaved relatives’ satisfaction with the CN service, but that this association does not extend to a positive evaluation of the palliative pathway. How do you account for this failure to extrapolate?

The satisfaction with the CN services is not the same as the satisfaction with the palliative pathway since a lot of other factors are at stake. This is described in the last paragraph of the section ‘Discussion of results and comparison with existing literature’
• Non-responders were significantly more likely to have had a deceased male, than female, relative die. What might explain this phenomenon, and do you feel that it may have skewed results?

Patients’ sex does not seem to have an effect on satisfaction with end-of-life-care (Ringdal (Ref nr 20 in the article) This has been added in the section ‘strengths and limitations of the study’, 2nd paragraph.

• Rationale for focus on cancer patients only could be provided, or the exclusion of non-cancer patients could be treated as a limitation in that it may limit generalizability of results. We rewrote the first paragraph of the section ‘Study population and sampling’. It now begins: ‘Since no database on palliative patients is available in Denmark, we decided to focus on cancer patients since these patients are included in validated Danish registers, and sampled the patients by combining official register data with questionnaires information.’

Reviewer 2:

Major compulsory revision

The first is what is a successful palliative care pathway? It is not spelt out just what this means, but this is the primary outcome measure of the project. I understand what is meant is a loose term to describe a mapping of the services tha were utilised by the patient during their final days.

In the fourth paragraph in the section of ‘Data collection’ it is now clear that ‘A successful palliative pathway at home’ is based on the relatives’ evaluation.

Is a pathway considered to be present only when the CN is involved, or can a pathway exist without CN involvement?

A pathway of course also exists without CN involvement, but in this case we only included cases with a CN involved since we wanted to look at associations with different factors of CN involvement.

Secondly, I am not at all clear as to the status of patients who died in nursing homes. The paper states that patients in care homes do not have CN involvement (p9 para 1). These are included as non-responders. However, should they not be excluded from any analysis? Subsequent analysis that shows statistically significant association between CN involvement are self evident and should not be in the paper (esp CN contact with relatives was lower in patients who died in nursing homes - this will of course be the case if the CN has nothing to do with them)

As we see it, there are two kinds of nursing homes residents. One group of patients was living at a nursing home even before the palliative period started, and those patients are excluded from the study, and the other group was admitted to a nursing home during the palliative period after a palliative pathway at home. This group is included in the analysis. We have clarified this in paragraph 1, page 9.

Minor essential revision

The questionnaires clearly have a lot of detail in them which has not been elaborated on in the paper - 60+ and 70+ item questionnaires clearly explored a lot of issues, but the
reporting brought these down to relatives' reporting of whether the palliative care pathway met their's and the patients' needs and expectations. I think the paper needs considerably more detail about the content of the questionnaire. The themes are now described in table 1. And it is clear in the text that only a small part of the data from the questionnaires is used in this study. (First paragraph of ‘Data collection’)

**Discretionary revision**
There are several minor changes in English expression which would improve the paper, but overall the quality of writing is on the whole very good. I would suggest asking a native English speaker to review the paper. The paper was once again sent to a thorough language review.

**Reviewer 3:**

I agree with the two reviewers that by definition, the main outcome (i.e. successful palliative pathway) and home death are likely to enjoy some measure of relationship- call it self evident association by definition. This concern is compounded by the problem of selection bias rightly acknowledged by the authors as a major weakness of the study. From the statistical perspective, two additional issues also present themselves: (1) “home death and “nursing home-death” may not sufficiently qualify as independent factors with respect to the outcome variable and

As we wrote above: As we see it, there are two kinds of nursing homes residents. One group of patients was living at a nursing home even before the palliative period started, and those patients are excluded from the study, and the other group was admitted to a nursing home during the palliative period after a palliative pathway at home. This group is included in the analysis. We have clarified this in paragraph 1, page 9.

(2) the sample size is not large enough to command sufficient power for any meaning conclusion from the estimates. Indeed, the acknowledged shortcomings of this study may account for the reported associations.

We recognise this lack of power in our study (See last paragraph of the section ‘Discussion of results and comparison with existing literature’), however it only strengthen the fact that home death is associated with ‘a successful palliative pathway at home’.

**Major Compulsory Revision:**
Address the problem of inherent dependency (by definition) between the main outcome and some of the factors being assessed for possible association with it.
This is now mentioned and discussed in the discussion section in the first paragraph of ‘Discussion of results and comparison with existing literature’.