Reviewer’s report

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

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Reviewer: Jane Wheeler

Reviewer’s report:

This is a succinct and interesting manuscript that describes a population-based, cross-sectional questionnaire study examining potential association between community nurse involvement in a patient’s care at end of life, place of death, and bereaved relatives’ evaluation of the palliative care pathway. Surveys were completed by community nurses (CNs), general practitioners (GPs), and bereaved relatives of 599 deceased cancer patients in Denmark. The derivation of the patient sample and the sample of bereaved relative respondents are very well-described in Figures 1 and 2. Primary data are presented as prevalence ratios; rationale for this approach is justified, and the presentation of data is clear and accessible in Table 3. The authors pose an important and well-defined question, namely, whether place of death and/or CN involvement in end-of-life care for cancer patients are associated with relatives’ positive evaluation of the palliative care pathway. Methods are appropriate and well-described, however, the study design contains a fatal flaw as described below.

Discretionary Revisions

The clarity and readability of this manuscript would be improved by having an editor perform basic “clean-up” of the language.

Methods

• Why were GPs compensated, but not CNs or relatives of deceased patients?
• 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.
• Text regarding the questions posed to relatives is repeated twice (“very well, well, fairly well, bad, very bad”); this redundancy can be removed.

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.

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.
• How were the questionnaires delivered – by mail? By personal delivery to the patient’s home? In a clinic or other health system setting?
• 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…”

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

Background:
• A more well-developed background section would provide better context for the study, support its rationale, and underscore the significant of results. 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.
• 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?
• 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.
• 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.
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.

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

• “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?

• 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.

• 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.

• 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.

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.

• 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.

• 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?
• 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.

• 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?

• 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?

• 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.

Level of interest: An article whose findings are important to those with closely related research interests

Quality of written English: Needs some language corrections before being published

Statistical review: Yes, but I do not feel adequately qualified to assess the statistics.

Declaration of competing interests:

I declare that I have no competing interests.