Reviewer’s report

Title: Transitions as experienced by persons in palliative care circumstances and their families - a qualitative meta-synthesis

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Reviewer: Christina Ramsenthaler

Reviewer’s report:

Overall suggestion:

The authors provide a comprehensive review of the inner process of adapting to a life-limiting illness from the patient's and the family member's perspective. The review presents an interesting and new model of how transitional processes are a function of role definition and coping processes at the end of life. Supporting and hindering factors as to successful adaptations and family functioning are extracted from the literature. Overall, I think that this review is of importance to the field. However, I also find three major problems with this meta-synthesis which I would like to encourage the authors to address. First, I think this review needs to be framed differently. In particular, I would not give it a heading of "transitions" but "coping processes - helpful and hindering factors in coping with transitions". Secondly, the search strategies seems to result in very narrow retrieval from the databases, unless the focus of the review really should have been on cancer only. I am afraid either the search strategy has missed crucial papers or the authors haven't fully defined the eligibility criteria they have ended up using in this review. Third, there seems to be an issue with transparency of the analysis as it is not possible to verify how the coding scheme translates into the findings of the review and in particular the model that was presented. The discussion needs to be completely reworked.

Major issues:

Background:

- Line 86, page 3: a repetition of the aim is not necessary as the last paragraph in introduction section states it clearly.

- The background section misses crucial information. In the beginning, the authors attempt to clarify what is meant by the term "transition". In addition to providing a rather short description of the term and then introducing a taxonomy of transitions with four elements, the authors should first define the term. Regarding the taxonomy - this is helpful but lacks explanation. For example, categories (c) and (d) do not seem to be disjunct since transitions in the healthcare setting can easily mean transitions in specific settings. It does not seem clear enough why these two categories are split.
- Fit of results and background section/objectives: The authors state that they want to focus on specific transition from curative to palliative. However, I don't see this described in the results. Transitions from receiving the diagnosis and trying to adapt to potential life-limiting illness are incorporated in the results, but transitions within the healthcare system and into specific settings are only implicitly incorporated in the results.

- The rationale that is provided for this review is very short. I believe that the authors are right in that a review with a specific focus on transitions is lacking. However, what is actually described as results are coping strategies around transition points and how patients and their family react and deal with uncertainty. In terms of uncertainty and how it can be captured, see for example Etkind et al. 2017 Palliat Med (I appreciate that this is not a meta-synthesis but a secondary analysis of qualitative data). I would like to encourage the authors to think in a more conceptual manner about trying to differentiate their chosen focus of transitions to related concepts like uncertainty and coping with advanced illness. If their intention is indeed to describe the coping process and helpful factors with a specific focus on how to prepare for and deal with crises in advanced illness and how transitions can be mastered, this should be stated. Given the information in the background section, the reader is misled to believe that a model of transitions of patients from one care setting into another is to be developed. I appreciate that the authors decided to focus on coping mechanisms. However, I would find it also interesting whether the included studies mention anything related to decision-making around transitions. In particular since the authors mention the occurrence of crises around transitions and then not explore how these crises translate into decisions regarding healthcare access and problems with this. Qualitative data could shed light on the reasons for why patients and their families cope or do not cope well with transitions within the healthcare system and what influences their care-seeking behaviour.

- An aside: The authors define the patient population in this meta-synthesis to be "persons with palliative care needs". However, it is not defined what precisely is understood by palliative care needs. This omission becomes apparent when consulting the Methods section and checking the eligibility criteria: the authors correctly define palliative patients as being described as such in the included studies but fail to describe exclusion criteria as to the disease group chosen for this review.

Methods:

- I am worried by the narrow search terms the authors used in their search for mainly qualitative studies. I agree with the focus on a palliative population but omission of the search term "advanced" has resulted in missing a potentially large amount of studies. For example, I was puzzled as to why no study of Marilyn Kendall was incorporated in the review. These studies are usually reported using "advanced illness" in the title and therefore will not have been picked up by the search. Equally there is a lack of qualitative studies published in the 2000s from Scandinavian researchers. Sand et al's Support Care Cancer 2008 study readily comes to mind. As an aside, the search strategy does not fit the overall aim of the review which - judging from the background information on types of transitions - would include the early transition from diagnosis to advanced illness to palliative status. An exclusive focus on "palliative" studies
(whatever they may be) limits the review to retrospective accounts of transitions. However, the very nature of the term "transition" implies a longitudinal set-up. Another question arises from contrasting or rather validating the results of this review with Penrod et al's finding from 2012. First, why is this study not included in the review? It would clearly meet the inclusion criteria. Second, it should be pointed out explicitly in the discussion section what this review adds to Penrod's findings. I appreciate that Penrod's model was derived from primary research and not a meta-synthesis, but it would be illuminating to know how this review either corroborates or negates some of Penrod's findings.

- Personally, I would have omitted the search terms of "patient" and "family" (and their synonyms) and rather used search terms for qualitative studies. See Gysels et al. (Palliat Support Care 2007) for search terms and how this can be done successfully. Combination of search terms for disease group and study design will easily retrieve studies that focus on experiences of family members and patients.

- Further, it seems puzzling that no restrictions on study design were imposed if the focus was on qualitative studies. I appreciate that qualitative components can form part of mixed methods research and therefore qualitative findings can be incorporated in experimental research. However, I find the statement of eligibility criteria rather weak. Later on, it becomes apparent that indeed there were only certain types of qualitative studies included. I would advise the authors to state these rules explicitly in their inclusion/exclusion criteria.

- It is mentioned that different checklists were used to critically appraise the methodological quality of included studies. The authors make no further mention of how this was achieved nor do they state or describe how the results of the critical appraisal informed their synthesis. Critical appraisal should not simply be an exercise done for the sake of having to do it. A decision needs to be made (and stated) as to how results inform the synthesis, for example are studies differentially weighted in the summary or synthesis according to their quality? Are studies excluded because they are of too low quality? (I am particularly worried about Clemmer et al. (2008, ref [17]) with only 4 participants. Although this seems to be an in-depth ethnographic studies, the sample size is very small.) I am particularly interested in whether case studies or case serie were incorporated in this review. According to the eligibility criteria they wouldn't be excluded.

- I find it interesting that the authors mix approaches of grounded theory with approaches from thematic analysis. Is there a rationale for doing this?

- While I appreciate that the steps of the analysis are detailed in the methods section, I still find it hard to understand how coding was done and how the coding scheme was developed. For example, it remains unclear whether the complete full-text of each study was analysed or whether some prespecified criteria were used to choose relevant sections. Given the diversity of included papers (e.g. the paper on terminal restlessness) it would seem prudent to narrow the included sections to those relevant to the aim of the study. Furthermore, the coding scheme is not described in the paper.
Please make sure to conform to PRISMA and similar reporting guidelines in your review. Ideally, use the checklist and go through the review to make sure you have included the salient parts. I know that PRISMA is geared towards meta-analysis and not meta-synthesis but I believe it is still helpful to check that the systematic review methodology was applied correctly.

I believe that according to the author guidelines on the BMC Palliative Care webpage a statement needs to be included as to whether ethical approval was needed for this study. They do not make a distinction between primary and secondary research, but simply say "research articles". Therefore, I believe it is needed.

Results:

- Reasons for exclusion of articles after titles & abstract screening would need to be stated (in the PRISMA flowchart). A rather large number of studies was excluded and it is difficult to replicate this finding because of missing information on reasons for doing so.

- The fact that original retrieval of studies was very low from databases (barely clearing the 2,000-mark) lets one question the readiness of the search strategy to capture the salient studies.

- Page 6: The sudden focus on oncological diseases/cancer was not made clear in the Methods section. Neither is cancer defined in the PICO criteria nor in the overall aim of the study to be the focus of this review!

- There are many aspects about the result section I very much like. However, I feel that really three disjointed parts are presented. First, there is the in-depth account of how transitions are coped with and experienced by patients and their families. Then there is the model of transitions (Figure 2) that only pertains to the caregivers (or subsumes the patient's experiences unquestioned under "family"). It would have been more interesting to see how patients and caregivers differ and to develop separate models for both groups. This would have been particularly interesting as transitions seem to be off between the two groups, see result section on page 8 - first sentences under the heading "Social Environment of Transitioning"). Then there are the tables that summarise the information presented in long form in the Results section, but which also include further information (and in a way constitute the "synthesis/analysis" part of the review). As a reader I find it hard to bring these three parts together as they provide slightly different results and are not described in their relation to one another. Furthermore, I cannot work out how the coding scheme looks like. Ideally, a description of the coding scheme would set off the results section which then also informs subheadings and a description of the categories that make up the coding scheme. The figure seems to integrate the findings pertaining to the caregivers that are presented in the text but I wonder how this integration was done? It would also benefit the reader to understand how categories where defined (what was the anchor definition of the category? How were codes assigned to a category?) Ideally, there should be a translation of methods into results with the coding scheme providing the summary of codes and findings. Could the authors provide more information on this?
I found it puzzling that if the aim of the research is on "transitions" than why are these transition points not characterised? Rather, I find a lot of personal reactions to transitions described in this meta-synthesis as well as the illustration of coping strategies. However, the reader is lost as to an understanding what constitutes a transition for palliative patients and how they recognise them as transitions. In the same vain, the paragraph on page 9 states "Encountering a crisis cannot be avoided but PP and FM can adjust their daily life actively to maintain normality." Why can crises not be avoided? How do crises relate to transitions?

A related point is that I find it questionable to discuss transitions and how they are coped with disregarding the underlying disease trajectory of the patient. Qualitative research by Kendall and other authors has demonstrated that success in keeping up normalcy, response shift/adaptation to different disease situations and coping with uncertainty are in part driven by the underlying disease trajectory which may differ substantially within and between disease groups (I am just thinking of COPD versus multimorbidity versus solid tumours versus haematological diseases (CML or lymphomas for example)). However, I don't find the authors reflecting on this point. This is interesting since Penrod et al. specifically organise some of their results according to the underlying disease trajectory and define different transition points with reference to this disease trajectory. I am wondering how well the findings in this meta-synthesis generalise to patients on different disease trajectories?

The results all seem to go into the same direction and confirm the overall model the authors developed. However, I am curious as to whether there were any results from original studies that did not fit into the model? Analogous to qualitative analysis, I would like to understand the "negative cases" that did not conform to the overall pattern.

I find the result section to be overly long and verbous. I am not sure whether this description of codes really is a "summary and synthesise". It seems to be the case that every aspect of the original papers for that code was quoted directly or in an indirect manner. The material could be shortened here and there. It would also be helpful to understand at which points within each category the original findings contradicted each other. This is sometimes stated, for example when processes of dyadic coping are described. But it could be done to a greater extent (see my preceding point/suggestion). The results section could be cut by at least one third in my view.

Discussion:

This constitutes the weakest part of the paper. A discussion should not be a mere summary of the findings already presented in the Results section. It remains unclear how their results relate to other research. They try to compare the results to other published meta-syntheses on related subject. It would have been particularly interesting to explore in this context how the findings differ from already published research. I am also questioning why the need for their meta-synthesis was not argued with regard to these already existing reviews in the background section. Particularly references [26] and [27] seem to be of relevance, given that their focus on coping strategies is similar to the present review.
It is not enough to state that a model was developed. I would very much like to understand how the coding scheme informed this model. Also - why does the model only apply to the caregiver and not the patient? How could differences in adaptation and coping processes between patients and caregivers be illustrated?

Crucial parts are missing from this discussion section; there is no discussion of own methodological limitations.

I would have found it interesting to relate the findings to Penrod's model, especially given the fact that it is cited as the model against which results and codes were validated. Particularly so, since Penrod and co-authors seem to include the nature of the patient's disease trajectory into their analysis. A comparison of the author's model to Penrod's model would illuminate some of the coping mechanisms and when they could be applied.

What is completely lacking is a notion of how the results might be of interest to a clinical audience. What is the clinical message of this review? I am afraid it remains a bit of an academic exercise, summarising that there are difference in the process of adapting to an advanced illness and that these are driven by different supporting and hindering factors. If I were to play devil's advocate, I would ask - so what? We knew this before. What is the new finding and how can this be applied in clinical practice? I would very much appreciate the authors' thoughts on this point.

It is a bit puzzling to not read anything referring to common coping theories if half of the review is about coping mechanisms.

Minor issues:

- line 101, page 4: "inclusion criterions" should read "inclusion criteria"

- Methods section: Please be careful as to the distinction between methods and results. On page 4, line 109 the authors report the number of studies that were included in this review. They also then present a description of included studies in a table. This section should be incorporated in the Results section of the paper.

- line 103, page 4: "identified records on eligibility" should read "for eligibility"

- line 121, page 5: "by familiarizing with the studies" should read "familiarizing oneself with the studies"

- Table 1: Problems with apostrophe (e.g. "PP" should probably read "PP's")

- line 170, page 7: "try to retain these feelings in endurable limits" should read "try to contain these feelings as much as possible"

- line 178, page 7: "as conformation of life" should read "as a confirmation of life"
- line 187, page 7: Holtslander et al. - this study is not referenced

- line 195, page 8: "own needs and not to engage themselves" should read "and not engaging with their own needs"

- line 203, page 8: "the person or care to someone else" should read "the person's care to someone else"

- The whole paragraph starting from line 193 contains some redundancy and could be shortened (e.g. citing praying as coping strategies of course implies that they draw strength from prayer)

- line 212, page 8: "additionally affected through" should read "affected by"

- line 224, page 8: "families can increase quality of life of PP" should read "the quality of life"

- line 225, page 9: "worries and uncertainty are often mediated" - mediated through what? A mediator is a variable through which one factor influences another factor. "Mediated" is not the correct verb here!

- line 232, page 9: "and give advice" should read "giving advice"

- line 248, page 10: "their role as patient when" should read "as patients"

- line 252, page 10: "Uncertainty refers to" implies a definition of uncertainty. I think the authors mean "uncertainty occurs when"

- line 265, page 10: "they answer with the condition of the person they care for" should read "they answer by describing the condition of the person they care for"

- line 271, page 11: "FM describe the relationship to a close PP as a "greater..." - this whole sentence does not make any sense.

- line 284, sentence: "course of the day as well as the identified processes" - please make into two sentences, overly long and incorrect relationship between subclauses

- line 288, "that they can stay at home or will not be lonely" - incorrect mix of tenses

- same line, "hope evokes..." - full stop is missing

- line 297: "phenomenon under PP" should read "among PP"

- line 306, "the will to live for the moment" should probably read "living for the moment" (omitting "will to")

- line 312: "perceive the present intensified" should read "in an intensified way"
- line 314: "PP´s recognition" should read "PP's recognition"

- line 327, "They seek for possibilities" should read "They seek possibilities"

- line 329, "Feeling oneself as embedded in nature offer" should read "Feeling oneself embedded in nature offers"

- line 337, "is also characteristic" - characteristic of what?

- line 337: "Doing something", even it is not known whether it will help - incomplete sentence, probably "even if it is not known"

- I stopped at this point to note grammatical mistakes and issues of style. I would like to suggest to the authors to use some English editing service. Related to the issue of writing style, there is lots of room for shortening this manuscript. Sentences are overly long and contain redundancies stemming from a literal translation of expression in the authors' native language into English.

Are the methods appropriate and well described?
If not, please specify what is required in your comments to the authors.

No

Does the work include the necessary controls?
If not, please specify which controls are required in your comments to the authors.

No

Are the conclusions drawn adequately supported by the data shown?
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