Author's response to reviews

Title: Implementation of improvement strategies in palliative care: an integrative review

Authors:

Jasper van Riet Paap (Jasper.vanRietPaap@radboudumc.nl)
Myrra Vernooij-Dassen (Myrra.Vernooij-Dassen@radboudumc.nl)
Ragni Sommerbakk (ragni.sommerbakk@ntnu.no)
Wendy Moyle (w.moyle@griffith.edu.au)
Marianne J Hjermstad (marianne.j.hjermstad@ntnu.no)
Wojciech Leppert (wojciechleppert@wp.pl)
Kris Vissers (Kris.Vissers@radboudumc.nl)
Yvonne Engels (Yvonne.Engels@radboudumc.nl)

Version: 2
Date: 15 May 2015

Author's response to reviews: see over
Dear Prof. Sales,

Subject: Revision of paper

We would like to thank both reviewers for their thorough reviews and useful feedback. We appreciate the opportunity to resubmit this manuscript for publication in Implementation Science. Please find a point-by-point response to the reviewers’ comments below.

Reviewer 1

1A) This is an integrative review which (compared to systematic reviews) is the widest type of review methods permitting the inclusion of all types of research designs (non-experimental and experimental designs) to bring light into the scope of the research topic. In addition, theoretical empirical papers are allowed. However, this approach requires a clear framework and restrictions by a systematic design. The manuscript includes a high number of articles (112), different settings/diseases and population/staff/multidisciplinary team, with different skills and education needs combined with different implementation procedures. This makes the comparison of implementation approaches, the presentation of results and outcome measures, and promotors and barriers quite impossible. Most of all, I feel that the interpretation of the studies is difficult and does not give the reader an answer to the aim of the manuscript which then could be an important piece in the puzzle of implementation research in palliative care.

\[\text{We understand the reviewers’ feedback and we agree that a comparison of 68 studies is not easy. However, the aim of this integrative review is to provide an overview of effective implementation strategies that have been used to improve the organisation of palliative care. We agree with the reviewer that it would facilitate the reader to introduce a further categorization in this paper as well. We have therefore extended } \text{table 3}. \text{ It now also differentiates the type of setting.}\]

2A) The reader gets the impression that palliative care for cancer patients includes the same approach/content compared to palliative care in nursing home settings and in people with dementia. This is not the fact. Compared to palliative care for cancer patients there is almost no evidence based (PICO) research results regarding Advance Care Planning, assessment and treatment of pain and
We agree that the content of palliative care for patients with cancer differs from palliative care for persons with dementia. Yet, despite the differences in disease trajectories, symptoms and needs, there are overlapping aspects regarding the organisation and content of palliative care. Besides differentiating table 3 according to the type of setting, we have also added a more detailed explanation in the discussion: ‘The included studies were conducted in a variety of settings (e.g. hospitals, nursing homes, hospices and primary care facilities). The provision of palliative care within these settings may vary depending on the patient group. Patients with cancer, for example, have a different disease trajectory, and other symptoms and needs than persons with dementia. Despite these differences, there are many similarities regarding the organisation and multidisciplinary character of palliative care. For all chronic, life-threatening conditions, palliative care entails a patient centred approach in which multidimensional interventions related to actual and future problems, needs and preferences are made.

The WHO definition of palliative care is therefore applicable for all patient groups. (World Health Organisation, 2002) The European Association of Palliative Care illustrates this by recommending a common approach for palliative care across settings. (Radbruch et al. White paper on standards and norms for hospice and palliative care in Europe: Part 1. European Journal of Palliative Care 2009, and Radbruch et al. White paper on standards and norms for hospice and palliative care in Europe: Part 2. European Journal of Palliative Care, 2010) In addition, 40 international experts agreed that there is no need to formulate disease specific quality criteria for the organisation of palliative care. (Van Riet Paap et al. Consensus on quality indicators to assess the organisation of palliative cancer and dementia care applicable across national healthcare systems and selected by international experts. BMC Health Services Research, 2014) However, this does not mean that there is ample evidence regarding effective strategies to improve (the organisation of) palliative care in the different settings. Hall et al, for example, described that there is limited evidence for palliative care service delivery for residents of care homes for older people. (Hall et al. Interventions for improving palliative care for older people living in nursing homes. Cochrane review, 2014) This illustrates the necessity to further improve the field of implementation science, in particular in underdeveloped areas such palliative care for persons with dementia.’ (page 13-14)

3A) The term “to implement” means to fulfill or to carry out into effect. “Implementation research” is defined as the related scientific investigation concerning the implementation process and the act of carrying an intention into effect in a “real world” scenario. I think that several structural factors may influence the implementation process and the outcomes, such as the measurement of change, information to stakeholders, guidance of decision making, or feedback. In order to the scope of this review these aspects are not mentioned. I miss descriptions of outcome measures and a reflection/discussion about the key question: how was change/improvement assessed?

We agree that a description was missing in the discussion on the assessment methods used in the selected studies regarding their changes and / or improvements. Although it is not possible to describe this in detail for all of the selected studies, we have included the following sentences in the discussion: ‘For this review, all reported outcome measures in the identified studies were extracted. These measures included several patient outcome data items (e.g. assessment of the percentage of patients in pain following an educational session about pain treatment) as well as data concerning the process of care (e.g. the frequency of patient referral to specialist care following the introduction of a new referral form), making comparisons of outcomes impossible. However, the aim of all included studies was to improve the organisation of palliative care. We therefore generalized the outcomes to the degree in which they aimed to improve the organisation of palliative care.’ (page 12)
4A) A crucial aspect when assessing the efficacy of a complex intervention study is whether or not the intervention was implemented at all. Even when an intervention is superbly designed, real-world contextual factors may prevent the intervention to be realized in a complex adaptive system as intended. This should have been a part of the discussion.

Indeed, implementation is a complex activity that needs to follow certain steps in order to be successful. We have included a paragraph in the discussion in which we describe the difficulty of implementation: ‘... Even when the intervention is well-designed, real-world contextual factors may prevent the intervention from being realized. Implementation of evidence-based and best practices should therefore always be guided by a step-by-step model in order to identify the problem, barriers and facilitators and tailored strategies to solve the problem. [ref: Grol] Integrated knowledge translation can then be used as a bridge in closing the gap between what we know and what we do...’ (page 14-15)

5B) I am astonished that important contributions to the literature and related articles are not mentioned, for example the Cochrane collaboration project by Hall S et al. Interventions for improving palliative care for older people living in nursing homes (review).

We were aware of its existence, but mistakenly did not include it in our discussion. Following the reviewers’ suggestion, we have thankfully included this review in the discussion (also see comment 2A): ‘... Hall et al, for example, described that there is limited evidence about palliative care service delivery for residents of care homes for older people. This illustrates the necessity to further improve the field of implementation science, in particular in under developed areas such as palliative care for persons with dementia.’ (page 14).

6B) There is a lack of intervention studies. This, of course, is not the fail of the author group. However, the reader will expect a detailed discussion of the studies content, comparison, quality description of the studies, detailed type of intervention, outcome measures, strength and weaknesses and future perspectives regarding research needs.

We agree that there is an insufficient number of intervention studies. A detailed description of the included studies can be found in appendix 2, where we describe the intervention as well as the outcome measures used. Appendix 2 does not include strengths and limitations of the included studies as these will be covered in a separate review (currently being conducted).

7B) Regarding the results: what’s about the remaining 36 studies (112 articles in total – 68 with positive/lack of effect = 36 articles remain)?

We agree that we unintentionally gave the suggestion that the remaining 36 studies would also be discussed in this review. We have adapted the methodology section, more explicitly stating that our focus was entirely at the experimental and quasi-experimental studies. The 'Data extraction and analysis' paragraph now also includes a statement regarding this: ‘... Because of the large number of studies identified, and the difficulty comparing and interpreting the results of all these studies, only studies with an experimental or quasi-experimental study design were selected for further analysis.’ (page 8).

Subsequently, we have adapted the first paragraph of the results, this paragraph now only mentions the numbers from experimental and quasi-experimental studies. In line with this latter change, we have deleted former table 2 from the manuscript.
8B) Finally, I was surprised about the following conclusion: “Strength of the study is that the results of this review are implemented in the development of improvement projects in five European countries”. I feel that this may be a circular argumentation...

Indeed, it would facilitate the reader when we provide more information about how the results presented in this review were used in the IMPACT project. We have therefore added the following text to the discussion: ‘... the results of this review will therefore be used in the EU funded 7th Framework IMPACT project. An intervention study investigating improvement projects with pre- and post-test-evaluations was performed in 40 services providing palliative care across Europe (including hospitals, nursing homes, hospices and primary care facilities). In this study, quality indicators were used to identify potential areas to improve the organization of palliative care. Subsequently, Grol’s Implementation of Change Model was used to guide the services in their quality improvements. The strategies described in this review were used as an example and if possible also as actual strategies regarding how to change the organization of palliative care.’ (page 15)

Reviewer 2

1) Coding and compilation of data from the subgroup classification into a matrix of effects, includes experimental and quasi-experimental studies only. This has been specified by the authors in the results section; could this information be moved further up into the Methods section, to facilitate reading of results?

Please see our answer to comment 7B of reviewer 1, explaining how this has been changed.

2) A stated strength of the study is the implementation of its results in the development of the IMPACT project. Are there any publications detailing the work described in this paragraph, if so, can they be referenced here?

The paper in which the IMPACT intervention and its result will be described will be submitted this spring, so a reference is not yet available. However, we have included a more detailed description regarding how the strategies have been used within the IMPACT project (please, also see our answer to comment 8B of reviewer 1).

3) The manuscript needs to be proofread (see for example penultimate sentence page 13) and edited for idiomatic errors (see for example line 13, page 13).

Thank you for pointing out these inconsistencies in the text. We have thoroughly revised the manuscript in order to improve the language and correct inconsistencies and grammatical errors.

We sincerely hope that our changes are satisfactory.

If you need further details on the IMPACT project or the currently submitted paper, please do not hesitate to contact Jasper van Riet Paap.

Looking forward to hearing from you,
Also on behalf of the other authors,

Your sincerely,

Prof dr Myrra Vernooij-Dassen, Prof dr Kris Vissers, Dr Yvonne Engels, Jasper van Riet Paap MSc