Author’s response to reviews

Title: Towards appropriate information provision for and decision-making with patients with limited health literacy in hospital-based palliative care in Western countries: a scoping review into available communication strategies and tools for healthcare providers

Authors:

Janneke Noordman (j.noordman@nivel.nl)

Liesbeth van Vliet (l.vanvliet@nivel.nl)

Menno Kaunang (menno.kaunang@gmail.com)

Maria van den Muijsenberg (M.vanderMuijsenbergh@pharos.nl)

Gudule Boland (G.Boland@pharos.nl)

Sandra van Dulmen (s.vandulmen@nivel.nl)

Version: 1 Date: 20 Feb 2019

Author’s response to reviews:

20 February 2019

Dear Editor,

Thank you very much for considering our paper for publication in BMC Palliative Care.

We are happy to inform you and the reviewers that we were able to incorporate almost all of their suggestions, which have led to a number of significant changes. Changes can be found in the new version of our manuscript (see track changes). Please find below a detailed reaction on all comments.

Kind regards,

On behalf of the authors,

Janneke Noordman

Reviewer comments and reaction:
Reviewer reports:

Yoshiyuki Kizawa (Reviewer 1): This is the scoping review to summarize available strategies and tools for HCPs for LHL patients in hospital-based palliative care. This is very important issue clinically and I think this review is very informative for both clinicians and researchers.

Thank you for this positive feedback.

Major issue:

1) Please describe the definition of hospital-based palliative care. Does this mean in-patient hospice care/palliative care unit or hospital based palliative care consultation or both?

Hospital-based palliative care was defined as both in- and outpatient hospital-based palliative care. We added this to the method section, selection process.

2) Why do you exclude the study about terminal phase of care and end-of-life care? I think it is important to include studies in EOLC. Please explain about this in the manuscript.

Our study focus is on palliative care according to the WHO definition (see ref 35): “Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

We excluded studies on terminal care, if separate from palliative care. In our view, the terminal phase is different from the palliative phase: the focus of care is different (i.e. palliative care is still about a qualitative good life, while the focus of terminal care is about dying) and the period is different (the palliative care period is longer than the short period of terminal care). If the distinction between palliative or terminal phase of care was not clear we included the study, as well as end-of-life care studies. We also added this to our limitation section.

3) Why do you conduct literature review that limit studies conducted in a Western country?

The number of studies that included this scoping review is very limited, so I would like to know why do you conduct literature search so narrow. I personally think there are not much difference between western and eastern countries about strategies and tools for LHL patients.

Thank you for your good question. We decided to only include studies from Western countries as this study is part of a larger study in the Netherlands, and we think that palliative care and the patient population in the Netherlands is more comparable to Western countries than other
countries. It should, however, be clear that we only focus on Western countries so therefore we added this to our aim, research question and title.

Reviewer 2 (Reviewer 2):

GENERAL COMMENTS:

Objective - to find strategies or tools that are most effective in supporting patients with limited health literacy in palliative care.

An important question to ask. I have not seen this question asked before. As the author(s) point out - important to meet the wishes and needs of the patient to achieve desired person-centred palliative care and shared decision-making. Also how this is compounded by the high demands posed on professionals regarding appropriate and effective communication.

Method - as this is an area little written about / researched, a scoping review was conducted and this is defined in the context of this difficult research question. A considerable number of data bases were searched together with the 'grey literature' and contacting experts in the field. Database publications were independently reviewed by two authors and disagreements were resolved by discussion. Keywords 'tools' and 'strategies' were not defined beforehand and post-hoc these was added to the inclusion criteria.

Results - of 218 non-duplicate publications identified from the databases, after selection, one publication remained for inclusion. In the grey literature of 626 publications, four publications were included and of the national experts who reported a total of 118 studies, no study was included.

Discussion - the possible deductions that can be made from the results are given together with the limitations and the fact that this is an area that requires further research. ie Future research should focus on which strategies or tools are (most) effective in supporting patients with limited health literacy in palliative care.

The figure, table and appendix 1 with search strategy are very helpful to the reader and appendix 2 in relation to the grey literature.

REQUESTED REVISIONS:

None required other than proof reading the manuscript

ADDITIONAL REQUESTS/SUGGESTIONS:
None required that I could find

Thank you for your review.