Reviewer’s report

Title: "An odyssey without receiving proper care" - Experts' views on palliative care provision for patients with migration background in Germany

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Reviewer: Jeanine Louise Suurmond

Reviewer's report:

This is a very interesting manuscript about an important topic. I would recommend publishing it, but there are still some problems that in my eyes need to be addressed.

Introduction

Although the introduction is clear I missed some information:

The researchers talk about similar studies in the UK, US and the Netherlands. I think I would describe the results of the Dutch studies, (eg De Graaf who described similar barriers experienced by care providers in providing palliative care to patients with Turkish background) because these results are about comparable patient populations (Turkish migrants) and as such there is not such a gap of knowledge as the authors seem to suggest.

Background p2, line 21 : Why do the authors use the term transcultural competence? In my eyes the term cultural competence is more widely used and referred to.

It would be good to have some background knowledge about migrants in Germany. Which ethnic groups, how long in Germany etc/ Who are the migrants / patients with migration background, that the experts talk about?

Method

p. 3 : Expert identification: Why did you interview 13 experts? Was data saturation reached or was 13 experts all there was?

P. 3 Line 14 : This sentence I did not understand: 'The interviewer (MJ) acted as a co-expert or as an expert outside the field (depending on the field of health care of the interviewed expert).' What is a co-expert? What do you mean with expert outside the field?
P. 3 Data collection: line 27, To the sentence: 'key topics were access to (palliative) care, difficulties in care and strategies to overcome problems, I would add 'with respect to patients with migration background.

Results p. 4

Although several results are interesting, this section did not convince me yet.

1. I was not convinced by theme 1 (sociopolitical). Although it is interesting to discuss the wider discourse or societal mechanisms, I was not sure what this all meant for the access to palliative care. What is the changing paradigm here? To more shared decision? Although the excerpt is interesting I did not understand most part it (what is pseudo-protection? What is meant by an encounter from the 60s? I think this theme needs more elaboration, and should address how and why were migrants not included and what the effect was on palliative care. Why was it difficult for organizations to be more diversity responsive?

2. I was also not convinced by the next theme on barriers with regard to user level. First it is stated that patients' care needs and wishes at the end of life are seen as similar regardless of migrant status, but then all kinds of differences are being discussed. What is similar then in the needs? Or are some needs similar and other needs different?

3. And as the title of this theme is 'Access barriers on user level': What are exactly the barriers here?

4. In the excerpt it is quoted that 'for those affected, this 'nothing can be done () is a death sentence'. This theme is not discussed here, but it seems to me a very important barrier.

5. P. 6 , line 7-11 (Starting with Specialized palliative care services should actively seek networks…): These issues are important but are solutions and not access barriers.

6. Theme 3 (Challenges) is devoted to 3 subthemes. This is the most interesting theme in my eyes. However, what is the difference with theme 2 about access barriers?

7. How do you explain the contradicting findings: Patients want direct communication (they want the doctor to tell them what to do) but they also want indirect communication (they want the doctor not to fully inform them, in other words to be indirect in communication about bad diagnosis/prognosis? And does this finding not belong under the subtheme of communication"?"
8. P. 7, line 12, it is stated that 'other factors were not considered relevant, leading to a risk to culturalize conflicts'. Which factors were that?

9. Interesting finding that nonverbal communication also stops. But how? Which nonverbal communication stops? Do you have an example?

10. P. 8 Again the term transcultural is used. Why? Why not cultural competence?

11. In my eyes the result section can be rewritten into a much stronger discussion of the most important results. I think I would focus on the 3rd theme (challenges). I think I would leave out Theme 1 because this is a paper in itself, and I would reframe results from Theme 2 in terms of challenges in Theme 3. I would then encourage the author to systematically describe what the main challenges are in access to and use of palliative care for patients with migration background.

Discussion

Although the authors raise important issues, I think the discussion could be more about what this study really adds to the body of knowledge. We already know a lot about barriers for migrants in palliative care. So for example how can we really address patient preferences? How can you as a professional give realistic information and also retain hope? There is for example some Dutch research about that by Mariska Oosterveld.

In addition I think the part about language barriers could also be stronger. In the Netherlands there are guidelines for care providers about the use of interpreters and it is recommended that professional interpreters are used in several occasions such as when complex information is given of when there is bad news for the patient. How is this in Germany? Are there guidelines? And if so why are they not used? Are interpreters free or who has to pay? How does a care provider arrange an interpreter? Is this easy? For example, when you state on page 10, in line 17, 'Baurer and colleagues state that underutilization of professional interpreters is not necessarily due to lack of availability', How is the availability of interpreters in Germany? And what is the problem then if it is not due to lack of availability? Do health care providers do not know about it? Do they know about it but underestimate the risk of language barriers or the risk of an ad hoc interpreter? Do they know about it but do not know how to use it? Do they overestimate their own capacities to talk across language barriers?

On page 10, you mention training as a way to solve the problem. However, the training you describe is very generalistic. How would look a training about palliative care and migrant patients? And can tell you more about the biographical sensitive approach. This seems interesting but I did not yet understand how this could help to improve palliative care.
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.

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