Reviewer’s report

Title: Caregiver exposure to critical events and distress in home-based palliative care in Germany A cross-sectional study using the Stressful Caregiving Adult Reactions to Experiences of Dying (SCARED) Scale

Version: 0 Date: 30 May 2018

Reviewer: Ai Oishi

Reviewer's report:

Overall

Thank you very much for conducting a study to tackle one of the most important topics in palliative care. Considering global aging and the increase of number of deaths, I guess how we can support family caregivers who take care of their loved ones at home will be a worldwide challenge for us.

In my opinion, a major problem of this study is the scale itself, which is not properly examined its validity. This makes it difficult to understand what this scale really measures and how we can interpret the results.

Also, if your aim is to develop a German version of the scale which can be used in German context, the process of the development should be precisely documented (which I think will make a whole different paper).

For these reasons, it feels this paper is not appropriate for publication for BMC palliative care.

Please note the following points;

1. It seems there are some unclear English expressions. However, as English is not my first language, I avoid pointing out the details. Please check the English expressions and styles by any other means.

2. I try not to comment on statistical treatments on this study as I feel I am not qualified to do so.
Method

Study Design and Sample

How many palliative care teams exist in the targeted area (Federal State of NRW) in total? How many percent would 49 teams be of the total palliative teams?

It is not clear how you counted the number of contacted family members. If you 'distributed' information materials 'as flyers', it would be impossible to count how many people receive the flyers. Also, did members of the teams contact all families who met the inclusion criteria during the recruiting period? Could you explain how you recruited participants in detail? A response rate you mentioned (P7 L148) is also questionable for the same reason.

It is also useful if you can provide reasons for refusal.

I would suggest putting numbers of respondents and other results in a result section unless you have any reasons.

The Stressful Caregiving Adult Reactions to Experiences of Dying Scale

I have some concerns with this scale. First, the validity of the scale was not examined either in the original study or in the current study. It seems to me it lacks reference points and that makes it difficult to interpret scores of the scale. You might want to explain Prigerson et al's findings of the relationship between scores of the scale and other conditions; major depressive disorder, complicated grief and quality-of-life impairment.

It might be useful to attach the SCARED scale as an appendix as Prigerson et al.

General health

There are a lot more possible caregiving-related factors which influence caregivers' general health such as perceived burden of care, patient conditions etc. Have you collected such information? Even if you haven't, it is to me worth considering discussing this point in discussion.
Results

P10 L219
'Abitur' seems to be a German word, but probably better not to use here as it can confuse international readers.

The SCARED prevalence, frequency and distress score

P11 L249 / P12 Table 2
It is difficult to see what SCARED total score/ frequency score mean. See the previous comment in Method section.

P12 L268 and about the SCARED Scale
You call 'feeling patient has had enough' and 'thinking patient has dead' as psychological events. However, precisely speaking, these are not external 'events' but how family members percept what happened to them. It is somewhat confusing to ask if fear and helplessness were evoked based on their perception as I guess to many people perceptions and emotions are interrelated and difficult to which cause which.

P14 Table 3
Daily (frequency score =1) is probably a typo? I guess it should be '3' not '1'.

Discussion

It would be useful if you can discuss the future implications of the study in discussion section. So called 'so what'

P16 L313-317
It seems you compared the frequencies of each event of your study with those in Prigerson et al's study which is not clearly stated and I only could find by looking at Prigerson's paper. Could you better clearly state it?

Not sure comparing the results with P's paper is to meet the aim…

P17 L333-336
If caregivers in hospices receive greater support, they should have less frequent exposure of undesirable events. So this discussion goes opposite direction I suppose.

P17 L336-338
You discuss that different healthcare systems, particularly differences in acceptance and coverage of palliative care services might influence on the frequency of the SCARED events. This is an interesting point and could you elaborate more? It is not clear how the differences influence on the results from what you have written.
I'm afraid I could not understand this sentence.

You say the SCARED Scale could serve as a screening tool, but to what would you hope to screen with the scale? Also, to use it as a screening tool, you would need a cut-off point. What would you discuss in relation to a cut-off point of the SCARED scale in using as a screening tool?

Why do you particularly mention that this is to use at early stage of palliative care?

I agree that it's desirable to conduct a study with larger sample, but why do you think longitudinal study is needed? It contradicts with what you mentioned in L356.

Regarding the response rate: As I mentioned in Method section, it was not clear how you calculate the response rate. I do not think you can discuss your 'low' response rate.

There has been some evidence that family carers appreciate the opportunities to participate in palliative care research such as following:


I'm afraid I cannot understand the following sentence.
"Thus, we could not control whether the palliative services had taken possibly preselection in the distribution of questionnaires"

But I imagine you're trying to say that there might have been gatekeeping by palliative care services (or by persons who are in charge of distributing information - you said in Method section that 'study information' but not 'the questionnaires' are distributed as flyers - if you distributed the questionnaires, please change the Method section accordingly)

I am not sure if you can conclude that family caregivers in your study had 'a high number of stressful events.'
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?
If not, please explain in your comments to the authors.

No

Are you able to assess any statistics in the manuscript or would you recommend an additional statistical review?
If an additional statistical review is recommended, please specify what aspects require further assessment in your comments to the editors.

I recommend additional statistical review

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Not suitable for publication unless extensively edited

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