Reviewer’s report

Title: Patient Reported Outcome Measures for measuring dignity in palliative and end of life care: A scoping review

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Reviewer: Shane Sinclair

Reviewer’s report:

This manuscript reports on a scoping review of the usage of PROMS in palliative care, with a specific focus on measures focused on dignity at the end of life. The authors scoping review used the methodology developed by Arksey & O'Malley, conforming to 5 of the 6 methodological steps, with the final step of consultation being beyond the scope of the paper. This is a strength of the article as many scoping reviews don't identify, let alone follow the specific steps. In addition to the scoping review, which traditionally focus on mapping the literature versus systematically appraising the quality of the literature, the authors developed (?) and applied an evaluative framework to assess the psychometrics, clinical responsiveness, and transferability. This tool (Table 5) was developed based on guidance from MORECare (addressing ethical issues in palliative care); PRISMA (initiatives and guidelines for enhancing end of life research); and OACC (a practical overview outcome measures used in palliative care practice). This review is novel in that 1) it seeks to formally evaluate PROMS within palliative care from both a research and a practice lens 2) It has a specific focus on the construct of dignity, which according to the authors is the first review of its kind.

Main issues:

1. I found the purpose and length of the background/introduction to be unclear and unnecessarily long (8 pages). This highlights one of the main issues of the paper—its focus and lack of brevity. While the authors provide both a rigorous overview of PROMs in palliative care (the majority of the 8 page introduction) and an assessment of the 7 PROMS related to dignity specifically, this is overambitious venture and convolutes the purpose of both scoping reviews (mapping the literature) and their evaluation of the quality and utility of PROMs related to dignity. As a result, the draft manuscript (inclusive of appendices) exceeds 100 pages. While much of the information contained within these pages is of good quality, it seems they are trying to do too much and may want to consider dividing the paper into two—1) a scoping review of PROMS in palliative care; 2) a critical appraisal of dignity related PROMS. If this is not possible, there are many paragraphs and sentences in the introduction and results that could be collapsed and/or modified for the sake of brevity. The narrative in the results section could be further honed, referring the readers to the table of results for the more granular details.

2. A second significant issue, is the evaluation framework that was used in appraising the dignity related PROMS. While the authors are to be commended for the forethought that went into the development of this evaluation framework, greater details needs to be provided on its
development (did the authors develop it? Was there a PROMS evaluation expert part of the team?), scoring (how is the total score out of 15 calculated? Is it the number of Y/N questions which according to my count is 17?) and the rationale for including clinical along with research evaluation criteria. In regards to this last point, while one would assume that a PROM has clinical applicability this may not necessarily be the case or its intended purpose at this stage of its development. For example, a well developed and evaluated PROM that is not at a stage of development to determine its clinical utility would underperform in comparison to a PROM that had average psychometric testing but had been hap-hazardly implemented into clinical practice.

3. Further to the previous point, another significant issue that needs to be addressed by the authors and potentially applied in re-evaluating of the Dignity PROMS is the EMPRO (Evaluating the Measurement of Patient-Reported Outcomes). The EMPRO (https://www.ncbi.nlm.nih.gov/pubmed/18194398) was developed by an expert panel for the specific purpose of assessing PRO's by applying recognized criteria to determine quality. Why did the authors develop a separate evaluation framework (which they note has limitations) when the EMPRO is available for these specific purposes? At the very least acknowledging the existence of the EMPRO and the rationale for not using it needs to be incorporated into the paper. The authors may want to consider applying the EMPRO to the 7 identified articles as a substitute for their framework, which were developed from guidelines that were not specifically focused on evaluating PROMS from a scientific perspective (PRISMA, OACC, MORECare). This may address the authors own acknowledgment of the shortcomings of their critical appraisal tool, including the interpretation and meaning of calculated scores (Line 747).

4. In the intro, they state that PROMs should be transferrable to diverse care settings (line 178). While this may be the hope, there is also value in developing PROMs that are focused on a particular care setting. Even when a more general measure is desired, this is not always feasible or advisable and is sometimes addressed by a revised measure after a secondary analysis investigating gender, ethnic, setting differences. In short this is an overstatement.

5. In the critical appraisal of the Palliative nursing Quality Measure, and a number of the other measures for that matter, one of the issues that isn't consistently mentioned is the lack of initial face and content validity using patients themselves. It seems ironic that while the end-user of this and other assessed measures are patients, very few patients were used in the initial development stages to insure that the final items included in the measure(s) are indeed the things that matter to patients understandings of quality care not healthcare providers or researchers apriori paternalistic assumptions. In addition to making note of this across each of the measures in the result section, this is a point that the authors may want to consider raising in the discussion section.

6. Why was the PDI (Patient Dignity Inventory) not included in this review? While there may be some sound rationale for not including it (i.e. it is not intended for clinical practice), it would be good to inform the readers about its exclusion as most palliative care researchers and clinicians would assume that it was an included measure.

Minor Issues:
1. Line 248- should read 'spiritual issues' not 'spirituality issues'
2. Line 454 The second 'n' in the word 'Questionnaire' is bolded
3. Line 512—focus groups consisting of whom--patients?
4. Line 550—please provide a n= for the number of nursing home resident participants
5. Line 551- (source)?
6. Line 559- in describing 39 items presented as experiences would this more correctly be termed a PREM (Patient Reported Expeirence Measure) vs. a PROM?
7. Line 568- who specifically reviewed the contributions from the think-aloud procedure? SMEs? Measures Experts? This would have bearing on the validity of the measure.
8. Line 589- consider removing 'give a good indication of' to 'test'
9. Line 590—consider replacing 'prevent' to 'limit' as it is unlikely that recall bias can be completely prevented.
10. Line 624- please consider providing the results of the validity and reliability tests
11. Line 687—consider removing 'quantitative' as it seems self-apparent in psychometric testing.
12. Line 690—based 'on' hospices should read based 'in' hospices
13. Line 706—consider collapsing this very short paragraph into the previous paragraph
14. In contrast to the large background/intro section the discussion/implications/limitations/conclusion is brief and could be further developed. In addition to the lack of patient involvement in the initial development of the reviewed measures to insure face and content validity, what other issues/recommendations can be made to inform future directions of PROMs in research and practice? This rigorous and onerous review deserves greater attention in this regard, as the authors likely possess wisdom and expertise in this area that would greatly benefit other researchers and practitioners.
15. Line 851- Please qualify on what basis are these tools 'appropriate for use in palliative and end of life research'. How is the unequivocal endorsement of these tools in research reflect in the scores derived from the critical appraisal tool, particularly those who scored poorly in terms of their validity and reliability? Wouldn't this suggest that they are not appropriate (or in need of further validation) before being used in palliative care research?
16. Table 2- the first inclusion criteria is that the outcome measure must have been subject to validity and reliability testing. Based on the reported results it seems that some of the included measures did not (or only partially)—why were they then included in the review?

17. Table 2- Further to the previous point of not including patients in the initial development stages of the reviewed measures, criteria 2 for inclusion was that the measure must be relevant to any patient experiencing an illness or concern...". How was this determined? Where patients asked if they felt it was relevant? Or was it the researchers who determined it to be relevant for patients?

18. Table 5—please provide a description in the manuscript or a footnote as to how the total score is calculated.

19. Table 6- The EMPRO provides a much more parsimonious and standardized format for reporting reviewed measures in a tabular format. The authors may wish to consider this.

20. Pg. 72 to 104—seem to be duplicates of the appendices. Please consider removing as 72 pages is already unnecessarily long.

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

Yes

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

Unable to assess

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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