APM ANNALS OF PALLIATIVE MEDICINE
AN OPEN ACCESS JOURNAL FOR HIGH-QUALITY RESEARCH IN PALLIATIVE MEDICINE
IMPACT FACTOR 2.595

Peer Review File
Article Information: https://dx.doi.org/10.21037/apm-22-9

Reviewer Comments

An interesting study. There a few points needing clarification.

Comment 1. Title: it does not seem to reflect what this study was about, as "methods" is rather broad. Could authors reformulate?

Reply 1. We have changed the title to read: "Considerations for collecting patient-reported experience measures (PREMs) in palliative care: Findings from a cognitive interview study."

Comment 2: Introduction - Page 2, lines 70-73 – could authors provide references for that statement.

Reply 2: We have added two references that highlight the most important cognitive impairments in our target patient population, and modified the sentence so that it more closely represents the specific results reported in these.

Changes in the text: "Palliative care patients' capacity to self-report on PREMs is likely to be compromised by negative impacts of disease and treatment on cognitive processing, including impairments in verbal working/delayed episodic memory from opioids (6); such effects can also fluctuate over time (7)."

New references:

6. Pask, S., Dell'Olio, M., Murtagh, F. E., & Boland, J. W. (2020). The effects of opioids on cognition in older adults with cancer and chronic noncancer pain: a systematic review. Journal of Pain and Symptom Management, 59(4), 871-893. e871.
7. Kurita, G. P., Benthien, K. S., Sjøgren, P., Kaasa, S., & Hjermstad, M. J. (2017). Identification of the predictors of cognitive impairment in patients with cancer in palliative care: a prospective longitudinal analysis. Supportive Care in Cancer, 25(3), 941-949.

Comment 3: Page 2, lines 73-79 – an extremely long sentence. Could authors rewrite?

Reply 3: We have divided this sentence into two at a suitable juncture.

Comment 4: The main aim of the study is confusing: is some parts of the manuscript it appears that cognitive processes will be studied, in other parts it appears that the

main aim is the development of a new PREM, and the actual aim reads "… explore cognitive operations (…) when completing a PREM in order to inform future methods for capturing experiences…" but what methods exactly? Or was the aim to develop a specific measure to test 4 cognitive operations, as the organisation of the results' section seems to suggest? Could authors clarify by stating the main aim and possibly secondary aims of this study?

Reply 4: We have rephrased our aim and clarified in our Methods as follows.

Changes in the text: Aim - "The current study aimed to explore cognitive operations among people with palliative care needs when completing a PREM focused on the care domains known to be important to this patient population in order to inform future administration of PREMs in this context."

Methods - "This paper focuses not on developing a specific new PREM but rather on distilling patterns in cognitive operations that have broader implications for questionnaire administration for this purpose."

"The study used a PREM developed under the auspices of the New South Wales Bureau of Health Information specifically to capture experiences of healthcare in the domains identified to be most important to palliative care patients, as described in the Introduction."

Comment 5 - Methods
Recruitment
Page 4, lines 135-137 – there is literature available for sample size calculation in qualitative studies. Please consider revising the literature. Here are two examples: Malterud K, Siersma VD, Guassora AD. Sample Size in Qualitative Interview Studies: Guided by Information Power. Qual Health Res. 2016 Nov;26(13):1753-1760. doi: 10.1177/1049732315617444. Epub 2016 Jul 10. PMID: 26613970.

Saunders, B., Sim, J., Kingstone, T., Baker, S., Waterfield, J., Bartlam, B., Burroughs, H., Jinks, C., 2018. Saturation in qualitative research: exploring its conceptualization and operationalization. Quality & Quantity 52, 1893–1907.. doi:10.1007/s11135-017-0574-8.

Reply 5: We are familiar with the concepts of 'saturation' and 'information power', which were developed for grounded theory and qualitative research more generally respectively. However, sample size requirements for cognitive interviews are less established, as stated in our Methods and affirmed by a recent book chapter on the "state of the science and future directions" for cognitive interviewing, which highlighted sample size requirements as an area in particular need of focus (Willis, 2018).

Reference:

Willis, G. (2018). Cognitive interviewing in survey design: State of the science and future directions. The Palgrave handbook of survey research, 103-107.

We have added uncertainty about sufficiency of sample size as a limitation in our Discussion as follows.

Change in the text: "In the absence of established guidance on sample size for cognitive interviews, we aimed for and achieved recruitment of 15 participants as a mid-range estimate from similar previous studies (12-17). However, a larger sample might have revealed further considerations for PREM administration, especially if we had been able to purposively sample from patients with a broader range of perspectives."

Comment 6: Data collection
Patient-reported experience measure
If there are existing PREMs then why develop another one? Why weren't any of the existing PREMs identified in the systematic review, specifically developed for palliative care patients, used in the present study? There is insufficient justification to having to fully develop a rather long (33 items) measure to use in this population, when there are others, developed and validated for this population. Additionally, this has a huge impact on the design of this study. By using a new PREM, which has not been tested for the specific population that has been developed for, how can authors trust the results of the interviews to test the cognitive operations? Aren't participants reacting to something that has not been tested yet? This introduces a huge bias in results. How can you tell that by using an existing, well validated and accepted PREM would not yield different results?

Reply 6: As stated above, this paper is not focused on developing a PREM but rather on learning more generalizable lessons for administration of PREMs in this healthcare context.

As stated in our Methods, our PREM was largely comprised of items from existing PREMs identified by a systematic review, and was subjected to initial testing of content and face validity via focus groups with patients/families and broader stakeholder consultation. No existing PREM was used in its entirety because none were found that include items necessary and sufficient to assess the domains of importance outlined in the Introduction and identified by previous systematic reviews. While there is one other PREM that has been recently developed by Saunders et al (2021) specifically to cover these domains, it is very brief and was not considered to provide sufficient depth.

Finally, it is worth noting that cognitive interviewing very often precedes further psychometric testing during questionnaire development, so our study is not unusual in subjecting a questionnaire without established properties to this process, albeit for a slightly different purpose.

Reference:

Saunders, C. H., Durand, M.-A., Scalia, P., Kirkland, K. B., MacMartin, M. A., Barnato, A. E., . . . Elwyn, G. (2021). User-Centered Design of the consideRATE Questions, a Measure of People's Experiences When They Are Seriously Ill. Journal of Pain and Symptom Management, 61(3), 555-565.e555. doi:https://doi.org/10.1016/j.jpainsymman.2020.08.002

Comment 7: Analysis
There is no mention of method, methodology used or theory guiding the analysis. Please provide this information. Also, the choice of cognitive interviews – a specific technique for developing and testing face and cultural validity of measures – again suggests that there is confusion regarding the main aim.

Reply 7: We have now more clearly labelled as theory the one developed by Tourangeau (1984) and most commonly used to underpin cognitive interviewing, as described our Introduction – namely, that completion of a questionnaire involves the 4 'operations' of comprehension, recall, judgement and response. For a discussion of this and alternative theories used by various proponents of cognitive interviewing see Willis (2004).

Cognitive interviewing has been used in a variety of ways to develop questionnaires beyond face and cultural validation (see Wright et al 2021 for a recent review), as well as to explore cognitive operations for a range of purposes and contexts beyond questionnaire development, including verification that consent is truly informed (Willis, 2006) and the development of complex interventions (e.g. Hirschey et al, 2021).

References:

Hirschey, R., Nance, J., Wangen, M., Bryant, A. L., Wheeler, S. B., Herrera, J., & Leeman, J. (2021). Using cognitive interviewing to design interventions for implementation in oncology settings. Nursing Research, 70(3), 206-214.

Tourangeau, R. (1984). Cognitive science and survey methods: A cognitive perspective. In National Research Council (Ed.), Cognitive aspects of survey design: Building a bridge between disciplines. Washington, DC: National Academy Press.

Willis, G. B. (2004). Cognitive interviewing revisited: A useful technique, in theory.

Methods for testing and evaluating survey questionnaires, 23-43.

Willis, G. (2006). Cognitive Interviewing as a Tool for Improving the Informed Consent Process. Journal of Empirical Research on Human Research Ethics, 1(1), 9-23. doi:10.1525/jer.2006.1.1.9

Wright, J., Moghaddam, N., & Dawson, D. L. (2021). Cognitive interviewing in patient-reported outcome measures: A systematic review of methodological processes. Qualitative Psychology, 8(1), 2.

Change in the text: "According to theory, completing a questionnaire is hypothesized to require respondents to engage in four cognitive operations, namely: understanding what each item is asking ('comprehension'), retrieving relevant information or knowledge from memory ('recall'), making an evaluation of each item based on this recall ('judgment'), and selecting from the available response options accordingly ('response') (10)."

Comment 8: Discussion
Page 8, Line 341 – could it be that participants displayed those difficulties because it was a draft measure, rather than a well established one? If so, this has implications in all points made in the discussion.

Reply 8: As explained above, this paper focused on the implications that observed cognitive operations have for administration of PREMs to palliative care patients more generally, rather than on the function of specific items.

Change in the text: We have added a sentence to our limitations section that reads as follows - "It is also important to highlight that we used a PREM without established psychometric properties, limiting potential to interpret our results beyond the item level within the context of evidence regarding scale structure and reliability."