Author’s response to reviews

Title: Equity and the financial costs of informal caregiving in palliative care: a critical debate

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Author’s response to reviews:

Associate editor: The paper in its current state has methodological limitations as noted by the reviewers. It does not fulfil the requirements for submission.

Author response: Thank you for this comment, we agree the paper does not conform to the requirements of a research article and it was not intended as such. The paper was intended to be framed in the debate format (which was removed as a submitting article type at BMC Pall Care shortly before we submitted). Following correspondence with the Editor Linda Gummlich we were advised to submit the paper anyway (as she felt the journal should still support the debate format), but to flag that it is a debate article and not a research article. Apologies if we have not made this clear. We acknowledge that the article is not sufficiently clear about the format, and we have amended various sections to more clearly situate the paper as a debate article (see title, abstract, final para of intro, first para of discussion). We have also included a limitations section where we acknowledge the limitations of our approach. We welcome further guidance on how best to present the article, given we do not claim it is a comprehensive review of evidence.
Reviewer #1

The subject of the paper is fascinating. However, I think that is present a critical methodological issue, which is: "how the papers mentioned in the discussion were reached and selected?". In my opinion, the best methodology to achieve the mentioned goals, it would be a Scoping Review or similar. Without a rigorous method to identify the literature that works the financial costs of informal caregiving, how can be guaranteed that we include all the papers and the review incorporate the more important evidence? The article does not give any information about the process of identification, screening, eligibility and any specific details on the papers included. Despite that we are in the presence of an critical topic in public health palliative care approach, it will be essential to review the paper to improve the strength it.

Author response: See above – this paper was not intended as a research article and therefore we did not undertake a robust scoping review. We have attempted to more clearly situate the article as a debate piece and have explicitly stated that we did not conduct a systematic or comprehensive review. However, we did draw on previous systematic reviews where available and the paper was written as a collaboration between subject experts and expert methodologists. We have made a more explicit statement of this approach which we hope helps to strengthen the rigour of the manuscript.

Reviewer #2

Firstly it remains unclear what is considered to be end of life. The terms end of life, palliative and dying are all used. What is the time frame this paper is about? And what is the difference with caregiving in severe chronic situations?

Author response: Thank you for this point, we agree that our use of terms is inconsistent and confusing. We have amended throughout to be more consistent, and now only use the term palliative care where possible. We have also provided a definition of this term for clarity (background – page 4).

Secondly I believe the topic is written from the perspective of a few countries, primarily in Great Britain. Because of the relation to the EAPC taskforce I had expected the paper to include more (varying and sometimes better) financial supportive systems in European countries. Information and evidence on that might be missing and in that case the context should be mentioned in the title or abstract.

Author response: You are correct and the perspective of the UK is more prominent in this article, and we recognise this is a limitation. Unfortunately due to a lack of translation we were not able to access significant data from other European countries. We have noted this in the abstract and background and have also recognised it as a limitation in that section.

Finally by combining both financial costs and equity issues, of which the latter also is on inequity in patients (and not only on family caregiving) I think the paper lacks some focus. I understand that inequity for patients relates to family caregiving, however to my opinion the authors may improve the manuscript by clearly emphasising (in-)equity related to the position of family caregivers.
Author response: Thank you for pointing this out, we agree it would give our paper more consistency to focus on carers (not patients). We have removed the section where we described a patient benefit (p8) and replaced this with information on a carer benefit. We have also ensured the focus on carers is made more prominent throughout (e.g. p8, line 173).

Could the authors pay some attention to the relation of education and equity? 
Author response: Thank you this is an important point. There is not very much data on education however it is related to socio-economic status so we have briefly discussed it in the same section as this (page 8/9)

Line 236: add the word 'care'.
Author response: Corrected