Author’s response to reviews

Title: Trauma to Transformation: The Lived Experience of Bereaved Parents of Children with Chronic Life-Threatening Illnesses in Singapore

Authors:

Oindrila Dutta (oindrila001@e.ntu.edu.sg)
Geraldine Tan-Ho (geraldinetan@ntu.edu.sg)
Ping Ying Choo (choopy@ntu.edu.sg)
Casuarine Low (low.casuarine@ntu.edu.sg)
Poh Heng Chong (pohhengc@hcahospicecare.org.sg)
Carolyn Ng (clyn16@gmail.com)
Sashikumar Ganapathy (sashi@clubrainbow.org)
Andy Hau Ho (andyhyho@ntu.edu.sg)

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Author’s response to reviews:

Dear Reviewers,

Thank you for your meticulous appraisal of our manuscript and your thoughtful suggestions. We have paid careful attention to your valuable feedback in revising the manuscript, and we hope it now meets the quality standards of BMC Palliative Care. Please find below a detailed description of the changes made to the manuscript, based on your recommendations.

Comments from the Editor

COMMENT:

Thank you for your patience. The original reviewer has been unavailable to review your revised manuscript and we had to seek additional advice via third reviewer. I agree with Reviewer 3 here, please address their comments and concerns here carefully during your revision.
RESPONSE:

Thank you for your kind consideration of our manuscript and for helping to facilitate the search for a third reviewer. We have now addressed the comments provided by him and we hope that it satisfactorily meets the standards of BMC Palliative Care.

Comments from Bruce Rumbold (Reviewer 3)

COMMENT:

It's good to see from the previous reviews attached that methodological and procedural issues have been clarified in this version of the manuscript. I do however have problems with aspects of the discussion and would like to see this addressed before the article is accepted for publication.

RESPONSE:

Thank you for taking the time to read our manuscript and assess it based on the previous reviews. We have addressed the concerns that you raised and we are optimistic that you will find the manuscript to be worthy of publication.

COMMENT:

It is claimed that this study makes a distinctive contribution to the literature because no other equivalent studies have been carried out with Asian (in this case Singaporean Chinese) respondents. The discussion claims that the study shows the importance of family and societal factors in providing bereavement support for Asian populations, and implies that this is a distinctive finding of the study. My problems with this are twofold. First, no evidence is provided for this claim about family: I would have expected it to emerge as a theme in analysis, but the themes that are identified and discussed do not include reference to family, except incidentally. In fact, the themes reflect the sorts of responses expected from a western population (as the supporting references show). Second, the need for attention to family and social support is just as evident in non-Asian populations (see Aoun et al for example). It's certainly not distinctive of an Asian population.
RESPONSE:

Thank you for sharing your valuable feedback. We have now made the following revisions to the manuscript in response to the important points that you highlighted.

First, we have explained clearly how the study data and the themes that emerged reveal the importance of family and societal factors in providing support for Asian populations. Specifically, the data in this study revealed that Asian parent-caregivers who were caring for their child living with a chronic life-threatening illness often relied on their spouse for pragmatic support to cope with caregiving (Sub-theme: Spousal interdependency) as well as on their extended family members and friends who had a collaborative attitude towards care provision for the sick child (Sub-theme: Relational coping). [Discussion section, page 29].

Second, we understand your point that family support is critically important for Western parents of children with chronic life-threatening illnesses, but the evidence (such as Aoun et al., 2018) suggests that emotional and psychological support from extended family members is an important coping resource for bereaved parents. As yet, it is unclear how Western parent-caregivers whose children are living with a chronic life-threatening illness perceive support and assistance from their family, as the evidence seems to suggest that they may both welcome the involvement of their friends and family (Davies et al., 2004) as well as refrain from sharing their caregiving burden and obligations with people outside the immediate family (Collins et al., 2016). On the other hand, for Asian parents in this study, it was found that support provided by spouses and extended family members was an important resource in their caregiving journey and tended to be instrumental in nature (which corroborates other studies on how Asian families cope with a problem - through pragmatic means that focus on finding a solution rather than exploring feelings and causes). Whereas parents in this study described their disenfranchised grief following the loss of their child whereby family members did not adequately acknowledge their grief and the intensity of their suffering (Sub-theme: Disenfranchised grief). It is reasonable to say that support from their extended family members and friends would have been helpful for Asian parents as they coped with the loss of their child, but it is possible that the uncommon nature of a child’s death and it’s perception as a catastrophic event as well as prevalent death taboos in the Asian culture prevented parents from receiving such support.

We have now revised the discussion so that these details are clearly explained to the reader. [Discussion section, page 30]. Once again, thank you so much for highlighting to us that this section needed more work. Your feedback has been invaluable and we are open to receiving more suggestions from you if you feel that further revisions are required in this section.
COMMENT:

It may well be that Asian populations access family and social support in different ways - but there is no data here to indicate this. On what I read here I suggest that the findings of this study are congruent with those reported for other non-Asian populations. If this study has found otherwise we need to see the relevant findings. It may be that the thematic analysis that was carried out was skewed because previous categories had not been sufficiently bracketed out. But if there is no further data to report, the discussion needs to be adjusted to focus on congruence, not difference, across Asian/non-Asian populations.

RESPONSE:

Thank you for your feedback and the useful suggestions. We have reviewed the data analysis and we do not see any other salient categories that would be pertinent to the research question. We have now revised the discussion and elaborated on our explanation of the existing data to provide the reader with more insight about the similarities and differences between Asian and Western parents in regards to family support both during the period of caregiving for their sick child and after the loss of their child [Discussion section, page 29-30]. We hope that you will find these details to be satisfactory.