Author’s response to reviews

Title: A Conceptual Model of Barriers and Facilitators to Primary Clinical Teams Requesting Pediatric Palliative Care Consultation Based Upon a Narrative Review

Authors:

Jennifer Walter (walterj1@email.chop.edu)

Douglas Hill (hilld@email.chop.edu)

Concetta DiDomenico (didomenico@email.chop.edu)

Shefali Parikh (parikhsh@email.chop.edu)

Chris Feudtner (feudtner@email.chop.edu)

Version: 1 Date: 30 Oct 2019

Author’s response to reviews:

Thank you for the opportunity to revise the paper. I will provide point by point responses below each comment.

Reviewer reports:

Linda Oostendorp (Reviewer 1): This manuscript addresses an important topic and a number of relevant inhibitors and facilitators are discussed in detail, supported by an illustrative case. Overall, I would recommend this manuscript for publication, however I feel that the manuscript would benefit from more signposting and information about the methodology used. While the individual paragraphs describing inhibitors and facilitators (pages 6-15) are mostly clear, it is unclear how these factors were derived, and why the authors chose to emphasise team level inhibitors and facilitators, and only briefly touch on individual clinician inhibitors (individual clinician facilitators are shown in Figure 1, but not described in the main text).

Thank you for encouraging further clarity in these areas. They are addressed individually below under each suggested change. We have also expanded slightly the discussion of individual inhibitors and facilitators to help with clarity and match the Figure 1.
Suggestions to improve clarity include:

- Changing the title to make clear this manuscript focuses on pediatric palliative care;

We have added “Pediatric” to the title, which is now: A Conceptual Model of Barriers and Facilitators to Primary Clinical Teams Requesting Pediatric Palliative Care Consultation Based Upon a Narrative Review

- Adding more information about the aim, why did the authors focus on team level factors?

Thank you for raising this question. We agree that both individual and team level factors are relevant to this decision, but chose to prioritize team level factors for this paper for 3 reasons: 1) pragmatic reasons of space, 2) there has been more discussion of individual level barriers in the literature and 3) because team factors may often override even individual decisions. In empirical work we’ve done with interprofessional oncology teams we have heard from many providers that they individually would advocate for subspecialty palliative care, however, other members of the team would prevent the consultation—using many of the factors we describe at the team level. Given the 1st author’s work in interprofessional teams, it seemed helpful to have a better description of the interprofessional team inhibitors and facilitators clearly described, which were lacking in the literature. Please see the added text on p5 “Because most care for complex patients happens in interprofessional teams, and the team dynamic substantially influences decisions like consultation with subspecialty palliative care, we have primarily focused on team level factors affecting consultation rather than individual level factors.” And the bottom of p5-6 we have more accurately characterized the previous literature by providing additional detail about the individual level inhibitors.

- Adding more information about the methods (presumably the inhibitors and facilitators were derived from a literature review);

We appreciate the suggestion to be more explicit about the methods used to derive our conceptual model. We have added a METHODS section on p3 which reads: “We developed a conceptual model for the team level inhibitors and facilitators of regoaling based upon our clinical experience and social psychology theories of individual and group behavior. We then conducted a narrative review of literature in the fields of palliative care, organizational psychology, and social psychology to identify relevant team behaviors around changes in team goals and team function. Searches were conducted in PubMed and PsychINFO for relevant articles.”
- The paragraph 'inhibited expression of sorrow/lack of social support' (page 9) would benefit from a more explicit explanation how this factor would inhibit referrals;

Thank you for identifying the need to be more explicit about this connection between negative affect around consulting palliative care and suppression of sorrow. We have added this sentence to make the connection clearer: p9 “Often the acknowledgement that a patient has a worsening clinical trajectory and may benefit from subspecialty palliative care will elicit feelings of sorrow among clinicians. However, many clinical teams have group norms about avoiding significant expressions of sorrow and thus the topics which may elicit them leading them to avoid discussion at the group level.”

- Adding a paragraph after the last facilitator on page 15 to describe Figure 1 and explain how the factors described in this manuscript were combined with the prior model. It would be helpful to add a footnote to Figure 1 to indicate that the right half of the model shows the prior model developed by the authors;

We appreciate this suggestion to be more explicit about how our previous research interacts with the work we are presenting here and have added a paragraph describing the parallel and intersecting aspects of the 2 theories we have proposed. We have added an additional paragraph on p 17 “In Figure 1, on the right hand side, we have distilled previous research on the inhibitors and facilitators of parent/family level regoaling (9-11, 97) with the newly described individual clinician/team level aspects of regoaling represented on the left. By demonstrating the interaction between individual experiences of regoaling for both clinicians and parents with other team members and family members as parallel and conjoined processes, we hope to show the complexity of factors that need to align for a successful involvement of sub-specialty palliative care teams. Individual clinicians’ experience of regoaling is impacted by team-team discussions just as parental regoaling is impacted by discussions with other family members. The articulation of which inhibitor may be causing either the team or family to decline palliative care involvement allows for more targeted strategies to mitigate those inhibitors. Future research can explore the ways that teams and families may respond to facilitators in light of confounding inhibitors for accepting subspecialty palliative care consultation.”
Adding more information about how the model can be used / clinical implications;

We have highlighted the need for future research into how these conceptual models can be operationalized to improve palliative care consultation. P18 “Future research can explore the ways that teams and families may respond to facilitators in light of confounding inhibitors for accepting subspecialty palliative care consultation.”

- Changing the conclusion in the abstract as this is not supported by the data and is different from the conclusion in the main text.

We have changed the abstract conclusion to be more in line with the main paper. P2 “Recognizing potential team level inhibitors to transitioning to palliative care can help clinicians develop strategies for making the transition more effectively when appropriate.

Minor textual suggestions

- The terms 'barriers' and 'inhibitors' seem to have been used interchangeably;

Thank you for identifying this. To avoid confusion we have changed all language to “inhibitors.”

- One of the inhibitors is described as 'Sharing Serious News as a Team' in the main text, while it is described as 'Sharing serious news within the team' in Figure 1;

Thank you for identifying this discrepancy. We have changed the figure to be consistent with the text.

- In Figure 1 the inhibitor 'Lack of social support' is described separately, while in the main text this is grouped together with 'Inhibited Expression of Sorrow';

To ensure the text matches the figure we have combined these two categories as they are combined in the text.
There are a number of small language errors throughout the manuscript, e.g. 'fictionalizeD' (page 3, line 8), 'a set a of ..' (page 4, line 6), 'clinical teams need to have A shared mental model … ' (page 11, line 8)

Thank you for pointing out these grammatical errors. We have done a thorough copyediting and have corrected these and others.

Anthony Herbert (Reviewer 2): Overall, a very well written paper.

The authors build upon their previous extensive research in this area.

They develop some observations, principles and applications of "advanced" levels of both individual and team function to enhance the implementation of palliative care in clinical paediatric practice (particularly referral at the right time).

There was no real description of method. Perhaps the authors could briefly described how they developed this manuscript. Step 1 - conceptualisation of a schema to better understand individual and team dynamics in referring to palliative care

Step 2 - how they sourced or identified articles for this manuscript

Thank you for encouraging a more clear description of the methodology we used to develop the paper. We have followed your suggestion and added a METHODS section which covers both our conceptual model and how we conducted our narrative review. Please see p3 and reviewer comment above.

The authors spend significant time looking at the facilitators and barriers to referral to specialist paediatric palliative care. Could they also briefly comment on the role of primary palliative care (e.g. providing knowledge and upskilling those primary paediatric teams, so they can also provide palliative care to their patients?)
We entirely agree that clinicians with strong primary palliative care skills are more likely to provide this kind of care to their patients and also refer to subspecialty palliative care when appropriate. We have added training in primary palliative care skills as a facilitator of individual regoaling on p6. “While these individual inhibitors exist, there are also individual level facilitators which support clinician regoaling (Figure 1 upper left quadrant) like training in primary palliative care (35, 38)”

I am uncertain what the best title for this type of research is. "Narrative review using a conceptualised case study to illustrate". Based on both reviewers’ comments we have adjusted the title to be more descriptive of the paper. The new title is: “A Conceptual Model of Barriers and Facilitators to Primary Clinical Teams Requesting Pediatric Palliative Care Consultation Based Upon a Narrative Review”

Page 3 Line 8 "fictionalized"

Thank you for identifying this grammatical error. It has been corrected.

The grammar of the case study is excellent.

Could the authors please comment on whether time constraints are ever a barrier to individual clinicians regoaling? Is there anything reported in the literature on this? Does this also seem to be a feasible barrier.

We agree that time pressure can be an inhibitor to individual and team regoaling. We have added the following text to page 6: “Clinicians are also under considerable time pressure to see a certain number of patients and families each day which may both increase the cognitive biases mentioned above(57-59), reduce their ability to consider alternative approaches(60), and make them reluctant to initiate difficult conversations about palliative care that may take an unknown amount of time.(46, 61, 62)”

and on page 8:
“Time pressure can enhance the tendency of a small number of group members to dominate the decision-making.”

Page 5 line 15 "support the parents in making a decision about whether to insert a tracheostomy"
Could the authors please comment on why a tracheostomy was being considered e.g. to facilitate secretion management, upper airways obstruction, need for mechanical ventilation (either at times of illness, or chronic)? I believe this would add depth and reality to the case, and thus enhance the reader's ability to engage with the theory that is being discussed.

Thank you for encouraging a more robust clinical story for the readers to follow. We had imagined that the patient would have increasing severity and frequency of central apneic episodes, which is consistent with many of the patients we have cared for after significant brain injuries earlier in their lives. This was described in more detail on p7 “The pulmonology social worker, who had followed the family for years, suggested that the medical team consult the palliative care team to support the parents in the tracheostomy decision given her increased frequency and severity of central apneic episodes.”

The paper draws out well many of the benefits of inter professional care, as well as some challenges associated with this type of care too. Well done in this context.

Thank you, it was one of the intentions of the paper to emphasize interprofessional teamwork.

Page 6 Line 2 ... Suggest: Hypoxic brain injury
Thank you for the suggestion, it was changed.

Page 8 line 42 - Could self-censorship, illusion of unambiguous, pressure on dissenters to conform be grouped together as “group think” - which has also been described in the literature (including other aspects of scientific endeavour e.g. space travel).

Yes, you have correctly labeled the phenomena we were describing and we have added the terminology “groupthink” to the section on p 9 “Cohesive groups in stressful situations may engage in a variety of maladaptive processes also known as “groupthink” (e.g., self-censorship, illusion of unanimity, pressure on dissenters to conform) to reach a decision that ignores contrary evidence. (86, 87)”
Clinical teams who seem family members as a problem to be overcome may end up rigidly adhering

Thank you for noting this grammatical error. It has been corrected

There are a number of strategies that can help teams work together and to consider palliative care before their patients are close to death. These include:

- building and maintaining a shared model of the situation,
- increasing mutual trust and constructive dissent,
- anticipating potential conflicts with families and working as a team to problem solve these
- making sure to regularly reevaluate goals as a team
- work together as a team to break bad news and
- recognising the importance of team flexibility.

Thank you for the suggested change, we have made it.

Instituting a continuity attending who can pose these questions What is an "attending"? Is this a physician or other health professional? This sentence was not clear to me.

We apologize for the lack of clarity, this may be an American-centric terminology. We have changed it to physician.

Sharing Serious News as a Team
The use of various roles within a meeting where bad or difficult news was discussed is excellent. The roles of "Facilitator", "information giver", "emotional support person" and "recorder" are great, and I have not seen this so well described in the literature previously. Well done.

Thank you

There were some helpful practical applications of team flexibility. For example. ... "they can ensure that all essential tasks are covered and fill in for each other even when an individual team member is overloaded or unavailable."

Figure 1 is a very complex diagram to read. However, the conceptualisation that the author's provide is complex and multi-faceted, so in this context the diagram is comprehensive. It did make me wonder whether a simpler format of the diagram could be developed in addition to the more detailed one.

We appreciate the need to better clarify all of the information that is being incorporated into the diagram. We have provide further explication of the different aspects of the figure throughout the document, especially with more clarification of the relationships across the domains in p17-18.