Peer Review File

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Reviewer A

Comment: Interesting and complete review. Given the huge amount of data collected and analyzed, it would be interesting to focus on one of the three major topics about Perinatal Palliative Care analyzed (clinical aspects, training caregiver perspective) In order to allow a more thorough analysis.

Reply: Thank you for this comment. We recognize that a large amount of data is collected and have evaluated splitting it into clinical vs training but feel that this approach lessens the key message that training gaps influence gaps in clinical care.

Changes in the Text: We have added a note in the limitation section addressing that by combining these topics we risk losing depth in analysis but feel that the benefits of addressing training and clinical care concurrently outweigh this limitation. Please see lines 621-624 where we inserted the wording "Next, our study intentionally focused both on palliative care delivery and training. It is possible that by combining these two important topics, we were limited in the depth to which we could assess either. However, we felt that the value added by doing a combined analysis of training and clinical care outweighed this limitation."

Reviewer B

Comment: The scoping review is well planned, and the search strategy is depicted clearly. The 4 research questions have been adequately answered.

Reply: Thank you for this supportive comment. We hope our manuscript contributes to the palliative care literature.

Changes in the Text: None

Reviewer C

Comment: Systematic scoping review synthesizing perinatal palliative care literature from low- and middle-income countries. This review offers an insightful perspective on the global approach to perinatal palliative care. As noted in the article, most current evidence is concentrated in high-income countries, which have distinct healthcare systems and cultural approaches. The review includes 81 studies from various countries, analyzing a wide range of themes that have been categorized into three main areas. In light of the growing body of evidence in perinatal palliative care, this review represents a valuable initiative to incorporate diverse circumstances and better inform future research priorities.
Reply: Thank you for this supportive comment. We hope our manuscript contributes to the palliative care literature.
Changes in the Text: None

Reviewer D

Comment: I really appreciated the authors' attempt to study the use of Perinatal Palliative Care in low and middle-income countries. It is a very important topic as Perinatal Palliative Care can be easily achieved even in very-low-income countries because it does not require special technological advances nor carries a significant financial burden. However, it requires education and training. Overall, the study is well done, clear and well written, however needs significant revision and here are my corrections and suggestions.
Reply: Thank you for this comment and for highlighting how perinatal palliative care is achievable in LMICs. We appreciate your section-specific comments and believe we have addressed them in a manner than strengthens the manuscript.
Changes in Text: See topic specific changes below.

Introduction.
Comment: The manuscript gives the impression that the authors are not very familiar with Perinatal PC as it originated in 1997 (1) and developed over time in academic institutions (2-4), but also in community hospital with much less resources (5) – just to quote some of the essential references, but there are so many more in current literature.

Reply: Thank you for this comment. We value the additional historic insight you provided. Given the heavy representation in the literature by high-income countries when describing perinatal palliative care, we did not go too deep into the history of program development or recommendations in this section, rather using your feedback to further focus on the origins of the field and the role perinatal palliative care now represents globally.
Changes in the Text: We have added several of these references, as well as other supporting historic documentation of perinatal palliative care, in the introduction. Please see lines 97-112 where we restructured the introduction to better provide historical context for perinatal palliative care. Please also see lined 79-82 where we introduced perinatal palliative care's role throughout the neonatal period earlier in the paper with the wording "We also emphasize that neonatal death can occur anytime in the first 28 days of life, and that many of the infants who pass away during this time period have clinical needs, such as relief from pain and agitation, that are encompassed in perinatal palliative care yet are distinct from end-of-life care."

Comment: On lines 70-79 the authors define Perinatal PC as "a care model that supports families experiencing a life-limiting diagnosis for their fetus or newborn, or families who have suffered perinatal loss". On lines 101-103 the authors expressed that the difference between Pediatric PC and Perinatal PC is pretty much just about bereavement: "Perinatal palliative care extends pediatric palliative care with an enhanced attention on bereavement, with the parent/family serving as the focus of many interventions rather than the fetus or newborn". This is a quite limited definition, because it does not take into consideration the real focus of this discipline, the newborns and their comfort, along with family's support. 'Palliative Care' is a branch of medicine that offers care to patients with estimated short life or terminally ill. In Perinatal PC the patient in question is the newborn with life-limiting condition or at end-of-life stage. Perinatal PC can be offered to newborns who live for minutes or hours in delivery room, or for few days or weeks because of their life-limiting condition or babies with serious condition in the NICU after redirection of goals of care. The American College of Obstetrics and Gynecology published in 2019 a document opinion with the following definition: "Perinatal palliative care refers to a coordinated care strategy that comprises options for obstetric and newborn care that include a focus on maximizing quality of life and comfort for newborns with a variety of conditions considered to be life-limiting in early infancy." (6) This is considered the standard definition of Perinatal PC. It is understood that Perinatal PC may include support of families when there is a fetal demise or a stillborn.

In these situations, the goal is mainly family support, but there are still interventions to be offered towards the baby's body, such as bathing, dressing, memories, etc. I suggest that the introduction needs to be largely revised as follows: shorten the narrative regarding palliative care and pediatric palliative care and give a larger space to Perinatal PC, according to its definition and practice.

Reply: Thank you for this comment and for sharing additional information about perinatal palliative care. We are familiar with the ACOG statement you provided and strove to emphasize how a large part of perinatal palliative care involves family support as well as ensuring that the reader understood that the families of stillborn infants need similar support. We appreciate your suggestion about deemphasizing the broader definition of palliative care and focusing more deeply on perinatal palliative care.

Changes in the Text: Please see lines 97-112 where we restructured the introduction to better define perinatal palliative care. We also removed less relevant text at line 81 that covered global targets for stillbirth and neonatal death but lacked focus on PPC. Lastly, we added an impactful reference on lines 120-122 where we say "Less is known about perinatal palliative care in LMICs; A 2023 integrative review of perinatal palliative care programs is emblematic of this research gap, as their search yielded 69 publications all of which were from high-income countries" as this underscores why defining PPC globally is an unmet research need."

Methods.

Comment: Research questions. First question relates to "Elements of Clinical Perinatal PC .…" – following my comments in the Introduction, I believe that this question has to do with clinical management of the newborns who are the objects of the care. What about offering bonding of mother/parents and baby, or comfort measure for the baby, or pain management, etc.. Did the authors search about these items in their articles' review? (see below my comment in Results)

Reply: Thank you for this comment. We did interrogate each article for mentions of pain management, pharmacological and non-pharmacologic support. While a few studies addressed this topic, it was primarily to characterize the need rather than to provide guidance or descriptions of current practices. It was therefore not featured in our original submission. Given your insightful feedback, we have added in our findings on this topic.

Changes in the Text: We have added a note that we searched and tracked comfort and pain management. See lines 222-223 where we inserted the wording "For each study we also documented if pain management was mentioned either for care while in the NICU or in the context of end-of-life care.". We have also included this topic in the results. See lines 251-253 where we inserted the wording "Across topics, 17 papers mentioned the need for or use of pharmacologic or non-pharmacologic approaches to pain management within perinatal palliative care. A majority, (n=14, 82%) of these studies classified pain and symptom management as a clinical or training gap."

Comment: Lines 160-162. I noticed that some essential keywords were missing such as: "comfort", "bonding" or other keywords related to newborns' treatment when PC was offered.
Reply: Thank you for this reply. We did not include those terms in our search strategy. While they are essential elements of palliative care, the terms comfort and bonding were thought to be too broad. The team was interested papers that addressed comfort and bonding specifically in the context of palliative care and felt that the search terms used for this study (ex: palliative) would pull relative papers. We do, however, recognize that excluding those terms could have led to missed papers.
Changes in the Text: We have added a note in the limitations section about how additional search terms, including "comfort" and "bonding" may have led to additional papers being included in the review. See lines 562-566 where we inserted the wording "Fourth, although we used a number of free-text and MeSH terms addressing perinatal palliative care provision and training, there is a possibility that non-reviewed studies that used other terms with similar meaning may have been overlooked. For example, our search did not include the terms "comfort" or "bonding", common components of perinatal palliative care provision but that we felt would be captured within articles retrieved using our selected terms.".

Results + Discussion + Conclusion
Comment: The first item is about 'clinical care'. Please refer to my comment above about the first research question. Did authors analyze 'what was the clinical support for the newborn' in those papers related to 'clinical care'? Was bonding with family or comfort offered? Was 'nutrition for comfort' or warmth or pain/distress management addressed? Since none of these essential items is mentioned there are 2 possibilities:

1. The authors did not search in their review for these elements and, if this is the case, they should re-review articles of interest and report on this essential part of Perinatal PC.
2. If the author searched for these items and did not find any mention in the articles of interest, they should underline this in the Discussion as a significant lack. In the discussion (lines 531-537) there is a brief mention about pain management and opioids, but this is just a small portion of the interventions that can be offered to achieve comfort to a newborn with life-limiting condition.

Reply: Thank you for this comment. We reviewed the articles for comfort measures, pain control, etc. The topics were minimally covered in the included articles, primarily being cited as "gaps". Nutrition was not mentioned in our reviewed studies. We agree with your suggestion to include this finding / gap in the results and discussion section. Most infants are not actively suffering and will die within days or weeks. Studies from high-income countries (7) show how important are these interventions to parents. Moreover, these goals are easily reachable, even in low-income country, because do not require a technological advances or are charged with financial burden.

Changes in the Text: See lines See lines 251-253 as described in a prior response. Additionally, we addressed this gap, and that of nutrition, in the discussion section. See lines 473-480 where we address the topics of pain management and nutrition.

Comment: Line 262. Typo: change 'Aisa' to 'Asia'.

Reply and Changes in Text: Thank you for this suggestion. This change has been made as suggested.

Comment: Line 486. Typo: change 'palliative care' to 'perinatal palliative care'.

Reply and Changes in Text: Thank you for this suggestion. This change has been made as suggested.

References

Comment: These are suggested references provided by the reviewer

1. Calhoun BC, Hoeldtke NJ, Hinson RM, Judge KM. Perinatal hospice: should all centers have this service? Neonatal Netw. 1997 Sep;16(6):101-2. PMID: 9325884.
2. Limbo R, Wool C. Perinatal palliative care. J Obstet Gynecol Neonatal Nurs. (2016) 45:611–3. doi: 10.1016/j.jogn.2016.07.002

3. Carter BS, Parravicini E, Benini F and Lago P (2021) Editorial: Perinatal Palliative Care Comes of Age. Front. Pediatr. 9:709383. doi: 10.3389/fped.2021.709383
4. McCarthy FT, Kenis A and Parravicini E (2023) Perinatal palliative care: focus on comfort. Front. Pediatr. 11:1258285. doi: 10.3389/fped.2023.1258285
5. Ziegler TR, Kuebelbeck A. Close to home: perinatal palliative care in a community hospital. Adv Neonatal Care. (2020) 20(3):196–203. doi: 10.1097/ANC. 0000000000000732
6. Committee on Obstetric Practice Committee on Ethics. Opinion no. 786: perinatal palliative care. American College of Obstetricians and Gynecologists Committee on Obstetric Practice, Committee on Ethics. Obstet Gynecol. (2019) 134:e84–9. doi: 10.1097/AOG.0000000000003425
7. Parravicini E, Daho M, Foe G, Steinwurtzel R, Byrne M. Parental assessment of comfort in newborns affected by life-limiting conditions treated by a standardized neonatal comfort care program. J Perinatol. (2018) 38:142– 7. doi: 10.1038/jp.2017.160

Reply: Thank you for these references. We have reviewed them and incorporated relevant literature as described in the sections above.

Changes in the Text: Literature incorporated as described above.