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RESEARCH

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Priorities for research in perinatal palliative care: an international Delphi study

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Abstract

Background Perinatal palliative care (PPC) addresses the complex needs of families facing life-limiting fetal or neonatal conditions through an interdisciplinary, family-centered approach. Despite growing recognition of its importance, there is a lack of systematically defined research priorities to guide the development of evidence-based PPC practices.

Objective To identify and establish research priorities for perinatal palliative care (PPC) using a Delphi method with international experts and parents who experienced perinatal loss.

Methods This Delphi study involved three Delphi survey rounds with experts and bereaved parents. Participants provided and refined research priorities across rounds. In the first round, participants provided suggestions for research topics spontaneously. Topics were analyzed using principles of thematic analysis and further rated and ranked based on their importance in two additional rounds of consensual scoring. Consensus was defined as a score above the mean from at least 75% of respondents.

Results A total of 125 experts and 10 parents who experienced a perinatal loss were invited to participate in the study. Response rate in the three rounds was 24, 31, and 34%. A total of 187 research priorities were initially suggested, resulting in 34 topics reaching consensus. Final rankings and priority topics were categorized into seven thematic areas: organization of care, decision-making and communication, staff support and education, ethics, symptom management, bereavement, and family experience.

Conclusions This study identified critical research areas in PPC, providing a roadmap for future research to enhance support for families and healthcare providers in PPC.

Keywords Perinatal palliative care, Research priorities, Consensus methods, Expert panel, Priority setting, Bereaved parents

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Background

Perinatal palliative care (PPC) represents a specialized approach to managing life-limiting or life-threatening conditions of the baby, focusing on maximizing quality of life for both the neonate and the family [1]. It is still an emerging field with evolving definitions and diverse program structures across settings [2]. The current state of research in this area reveals a growing recognition of the need for comprehensive, multidisciplinary care that integrates obstetric, neonatal and other relevant services with palliative care principles. This integration is crucial as it allows families facing difficult diagnoses to receive coordinated support that addresses their emotional, spiritual, and physical needs throughout the pregnancy and beyond [1, 3, 4]. Recent studies have highlighted the importance of establishing effective perinatal palliative care programs, which typically involve a team of healthcare professionals, including obstetricians, neonatologists, and palliative care specialists, to ensure that families receive holistic care tailored to their unique circumstances [1, 5, 6]. The growing importance of collaboration between perinatal services and hospices has been identified [7]. Studies have also shown that many healthcare providers express a need for enhanced education and training in PPC to improve their competency and attitudes towards providing care [6, 8, 9]. Furthermore, qualitative studies have begun to explore the experiences of families receiving PPC, revealing that many parents value the support provided during such challenging times [10].

Despite the increasing acknowledgment of PPC's significance, there remains a notable gap in systematic research prioritization within this field. A bibliometric analysis indicated that while the volume of literature on PPC has been rising, it is still relatively nascent, with foundational concepts emerging only in the late 1990s [11, 12]. This lack of established research priorities is particularly evident when compared to broader palliative care research, which has seen more comprehensive frameworks and guidelines developed over the years [13–15].

Methods

The aim of this study was to define research priorities for perinatal palliative care using a Delphi method with an international expert panel. The Delphi method has been successfully employed in various healthcare context to establish research priorities, demonstrating its versatility and effectiveness [16–18]. It has been also previously used to define priorities for research in paediatric palliative care [19–21]. CREDES reporting guidelines for Delphi studies in palliative care [22] will be used to report the conduct of this study.

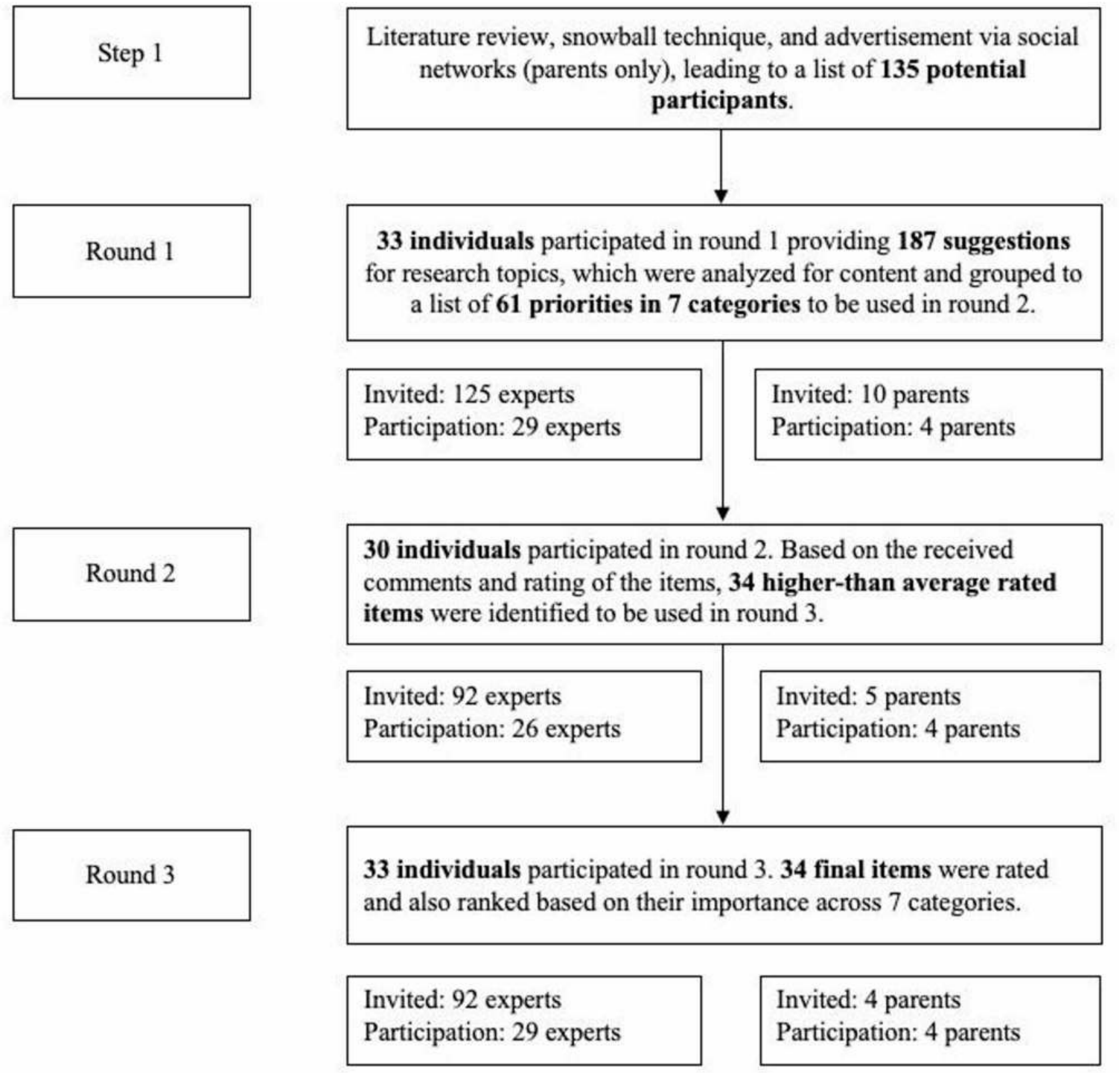
Expert panel

Using databases Scopus and Web of Science, we conducted a basic literature search looking for studies using the keywords „perinatal OR neonatal AND palliative". From each database, we looked at the corresponding and last authors of the 30 most cited articles, excluding duplicates between databases. Using this process we identified 82 experts. During the first round of the Delphi process, we used the snowball technique asking identified participants to nominate additional experts in perinatal palliative care who should be also invited to the study and 43 experts were identified in this way. Following user-involvement principles [23]aiming to strengthen the perspective of recipients of heath care services in the formulation and conduct of health research, parents who experienced perinatal loss were also invited into the study via social networks of our institution. The study was approved by the institutional Research Ethics Committee (protocol number 012023).

Procedure

Panel consisted of 125 experts and 10 bereaved parents who indicated interest in participation in the study. Each participant was emailed information about the aim of the project and the process of conducting a Delphi study, including expected number of at least three rounds of surveying their views. The email also contained link to a survey tool, developed in Click4survey, leading to the first round of the Delphi. On the first page of the online survey, participants provided their informed consent.

The first round was explorative, and participants were asked to provide 3–10 topics that they currently consider to be priorities for research in perinatal palliative care. We also asked the participants to provide information about their profession and specialization, how much research work they do (0–9, 0 doing no research, 9 being a full-time researcher), gender, and country of residence. For the second round, the topics suggested by the participants were categorized using principles of basic content thematic analysis and participants were asked to rate their importance on a 10-point scale. They also had a chance to provide a commentary or suggestion to reformulate each suggested topic. For a topic to be accepted for the next round, it would have to receive more than average score from more than 75% of participants, which is a recommended level for achieving consensus in Delphi studies [24]. In the third round, participants were also asked to rank the items according to their importance, regardless of their thematic category to identify the most important topics across the categories. All participants were invited to all rounds of the study if they did not indicate that they want to be excluded from the participation database. The overall procedure is illustrated in the flowchart in Fig. 1.



Literature review, snowball technique, and advertisement via social networks (parents only), leading to a list of **135 potential participants**.

33 individuals participated in round 1 providing **187 suggestions** for research topics, which were analyzed for content and grouped to a list of **61 priorities in 7 categories** to be used in round 2.

Invited: 125 experts
Participation: 29 experts

Invited: 10 parents
Participation: 4 parents

30 individuals participated in round 2. Based on the received comments and rating of the items, **34 higher-than average rated items** were identified to be used in round 3.

Invited: 92 experts
Participation: 26 experts

Invited: 5 parents
Participation: 4 parents

33 individuals participated in round 3. **34 final items** were rated and also ranked based on their importance across 7 categories.

Invited: 92 experts
Participation: 29 experts

Invited: 4 parents
Participation: 4 parents

Fig. 1 Flowchart of the study

Results

In the first round, out of 125 invited experts and 10 invited parents, 29 professionals and 4 parents completed the first round (response rate 24%). Demographics of participants in each round are provided in Table 1.

In the first round, participants provided 187 suggestions for priorities in perinatal palliative care research. After the content thematic analysis, a list of 61 priority topics grouped in 7 categories was developed for the second Delphi round. Categories were: organization of care, decision making and communication, staff support and education, ethics, symptom management, bereavement, and family experience. In the second round, out of 92 invited experts and 5 parents, 26 professionals and 4 parents provided their responses (response rate 31%), identifying 34 higher than averagely important topics that reached the consensual agreement of 75%. The average score was 7.5. Categories and priority topics identified in the second round are described in the Table 2.

In the third round, out of 92 invited experts and 4 parents, 29 professionals and 4 parents participated (response rate 34%), providing final scores for the identified topics and ranking them across the thematic categories. After the third round, consensus was achieved on all items. Top ten items across the disciplines are described in Table 3.

Table 1 Participants' demographics and response rates across the Delphi rounds

	First round (*N* = 33)	**Second round (*N* = 30)**	**Third round (*N* = 33)**
Profession			
Physician	17 (52%)	15	18 (55%)
Nurse	10 (30%)	9	10 (30%)
Psychologist	2 (6%)	2	1 (3%)
Bereaved parent	4 (12%)	4	4 (12%)
Research experience 0–9 (mean, SD, excl. parents)	6 (SD 2,58)	7 (SD 2,6)	6 (SD 2,3)
Gender (female)	26 (79%)	23 (77%)	25 (76%)
Region			
Europe	24 (72%)	23 (69%)	20 (61%)
North America	4 (12%)	5 (15%)	5 (15%)
South America	1 (3%)	1 (3%)	2 (6%)
Asia	1 (3%)	0 (0%)	1 (3%)
Australia	3 (9%)	1 (3%)	5 (15%)
Response rate	24%	31%	34%

Discussion

In this study, we aimed to identify key research priorities for perinatal palliative care. Based on the results of three Delphi rounds with a panel of international experts and parents who experienced perinatal loss, we identified seven thematic categories: organization of care, decision making and communication, ethics, symptom management, staff support and education, bereavement, and family experience. Thirty-four specific topics have been identified within these categories.

The need to explore models of delivery and organization of perinatal palliative care services, which was identified as the top priority topic, is consistent with results of several studies highlighting the complexities and challenges associated with providing effective care for families facing life-limiting conditions of their baby [3, 25]. Perinatal palliative care necessitates a well-coordinated delivery system that can adapt to the varying needs of families and healthcare providers and requires palliative care principles being met at both specialized and generalized level [26, 27]. Dombrecht et al. [25] conducted an integrative review that identified essential components of PPC, emphasizing the need for structured care delivery models that can effectively address the complexities of perinatal loss and support families through their grief. Moreover, current availability and structure of the PPC programmes vary extensively across as well as within countries [28–30].

The second top ranked topic was researching ethics of perinatal palliative care. In perinatal palliative care, parents face difficult decisions regarding continuation of their pregnancy, uncertainties about its outcome and care that will or not be needed [31–33]. Another ethical issue pertains to the role of healthcare providers in guiding families through these difficult choices. Grauerholz et al. [8] discuss the moral distress that healthcare professionals often encounter when navigating the varying values and desires of patients regarding their care trajectory. This moral distress can arise from conflicts between the medical team's recommendations and the family's wishes, particularly when there is uncertainty about the prognosis or the effectiveness of interventions [34].

In some aspects, especially identification of the broader areas for research, our results are consistent with other studies that focused on identification of research priorities for palliative care. Hasson et al. [13] identified the following priority areas: service models, continuity of care, training and education, inequality, communication, living well and independently, and recognising family/carer needs and the importance of families. However, they excluded issues related to children or any other sub-population with specific needs. In their work on priorities for pediatric palliative care, Baker et al. [35] identified 5 areas: decision making, care coordination, symptom management, quality improvement, and education. However, any specific issues related to perinatal palliative care have not been mentioned or identified in their study. Delphi study by Downing et al. [19] focused on global research priorities in children's palliative care identified perinatal care as one of the topics under their "clinical care" area, but did not provide any further comments on how this topic should be approached or further explored. Beside the similarities in the overall areas of study, our results provide identification of the key issues in the field of perinatal palliative care, acknowledging specific issues that would not be found in the more general models, such as the use of sedation in perinatal palliative care, that has been repeatedly lacking in the guidelines for palliative sedation [36, 37].

Despite the strengths of our study, several limitations must be acknowledged. The reliance on expert opinion

Table 2 Categories and priority issues 2nd Delphi round

Organization of care	**Average score (0–10)**
How to best offer perinatal palliative care (PPC) interventions to families? How, when, in what circumstances and who should offer it?	8,6
Developing prognostic tools and approaches to identify families that may benefit from PPC.	8,5
What is the optimal design of PPC service? What is the ideal pathway how to implement PPC service within a health care system?	8,1
Identification of barriers in offering and providing PPC and what helps to overcome them	8
Mapping the attitudes and practices of obstetricians towards PPC	7,9
Decision making and communication	
What information is essential for parents to effectively engage in advance care planning?	8
Effective models of shared decision making - what is the best way to share decisions with families?	7,9
Developing and testing interventions to decrease stress and anxiety among parents and family members around birth and early EoL decision-making	7,9
Exploring the process of continuation and reconsideration of decisions taken during the newborn period into the infancy	7,6
Factors affecting decision-making regarding life-sustaining treatment	7,6
How to share serious news effectively and sensitively with families?	7,6
Staff support and education	
How to support the wellbeing of staff involved in PPC?	8
Staff experiences with providing PPC - what experiences, conflicts and hard situations do professionals face and what helps to overcome them?	7,9
What are the factors that create barriers and enablers for medical professionals to get involved in PPC?	7,7
Evaluation of health care professionals' knowledge and training needs with regard to PPC	7,5
Ethics	
Ethics of decision making in PPC	8
Symptom management	
Pain management - pharmacological and non-pharmacological - what interventions are used and how effective they are?	8,7
Development of evidence-based palliative sedation guidelines for PPC	8,7
The safety and efficacy of medications (including evidence for preterm infants and those with organ failure)	8
Use of morphine and other opioids in perinatal palliative care– safety, barriers, attitudes	8
Management of symptoms in extremely preterm infants	7,9
Management of symptoms and support of families when the baby has complex congenital heart disease	7,6
Bereavement	
Exploring the bereavement process following perinatal loss and how does PPC influence it	8,2
The effectiveness of various forms of grief counselling for parents experiencing perinatal loss	7,8
The impact of parents' grief over an infant's loss upon future pregnancies and child rearing practices	7,8
Exploration of tissue/organ donation, milk donation and other legacy opportunities for families	7,8
Specific bereavement needs when a baby from a multiple birth dies	7,7
Developing and implementing a post-palliative care follow-up service and testing its effectiveness including a health economic evaluation	7,7
How to support families with multiple losses (e.g. due to congenital diseases)?	7,6
The role of rituals in perinatal palliative care	7,6
Family experience	
What difference does PPC make in the long-term well-being of families (mental and physical health)	8,7
Supporting both parents equally. How to support their partnership.	8,1
What is the experience of other family members (grandparents, siblings, etc.) when a couple receives a diagnosis of a life-limiting fetal diagnosis?	7,6
Spiritual needs and support for families in PPC	7,6

through the Delphi method may introduce bias, as the perspectives of families who have experienced perinatal loss were not as extensively represented in the consensus process. Additionally, the response rate in our study was on the lower limit. Although we did not collect the reasons for non-participation systematically, several invited experts confirmed that they have moved to another field since the publication of their articles and did not feel appropriate respondents for our study anymore, which corresponds with the emerging nature of this area. Also, most experts who participated in the study, were based in Europe, which could possibly influence the topics or prioritization process. However, even a recent study by Abayneh et al. [38] from Africa (which as a continent was

Table 3 Top 10 priorities for research in perinatal palliative care

Topic	Category
1. How to best offer perinatal palliative care interventions to families? How, when, in what circumstances and who should offer it?	Organization of care
2. What is the optimal design of perinatal palliative care service? What is the ideal pathway how to implement perinatal palliative care service within a health care system?	Organization of care
3. Ethics of decision making in perinatal palliative care	Ethics
4. What information is essential for parents to effectively engage in advance care planning?	Decision making and communication
5. Effective models of shared decision making - what is the best way to share decisions with families?	Decision making and communication
6. Management of symptoms in extremely preterm infants	Symptom management
7. Identification of barriers in offering and providing perinatal palliative care and what helps to overcome them	Organization of care
8. Pain management - pharmacological and non-pharmacological - what interventions are used and how effective are they?	Symptom management
9. Evaluation of health care professionals' knowledge and training needs with regard to perinatal palliative care	Staff support and education
10. How to share serious news effectively and sensitively with families?	Decision making and communication

not represented in our sample of experts) supports the importance of research topics such as communication, decision making or bereavement that we identified also in our study, supporting their cross-cultural importance.

Conclusions

By identifying key research priorities, this study provides a roadmap for future investigations that can directly inform the development of clinical practice, service organization, and education in PPC. The identified priorities highlight specific gaps in knowledge and care delivery that, if addressed, could lead to more timely, equitable, and family-centered support for those facing life-limiting fetal and neonatal conditions. These findings offer practical guidance for healthcare systems and policymakers seeking to establish or enhance PPC programs and underscore the importance of interdisciplinary collaboration in shaping comprehensive care models. Moreover, our results stress the urgent need for systematic education and training strategies that prepare professionals across disciplines to respond competently and compassionately to the complex needs of families. By translating these priorities into action, the field of PPC can advance in ways that are both evidence-informed and responsive to the lived experiences of patients, families, and care providers.

Abbreviations

PPC	Perinatal palliative care

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12904-025-01845-9.

Supplementary Material 1

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Author contributions

ML conceptualized the study and led the development of the manuscript. MZ coordinated the data collection and analysis. HMD and ZS were involved in the interpretation of the results and clinical implications. All authors read and approved the final manuscript.

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Data availability

The data used in this study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

This study was approved by Institutional Review Board of the Center for Palliative Care (protocol number 012023). All participants provided informed consent to take part in the study. The study was conducted in compliance with the WMA Declaration of Helsinki and its principles for ethical conduct of medical research with human participants.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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