



Citation lists are generated by [PedPalASCNET](#) through monthly searches of PubMed, Medline, and Embase. Visit our [blog](#) to see additional monthly commentaries on selected articles.

Trends in Pediatric Palliative Care 2017; Issue #11

Posted to PedPalASCNet's website on *October 31, 2017*

By Gail Teachman, PhD, OT Reg. (ON)¹; Raissa Passos dos Santos, RN, PhD student²; Stephanie Avery, RN, MScN student³; Konstantinos Mastorakis, PhD⁴; Crystal Noronha, MSc, Coordinator, Pediatric Palliative Care Research⁵; Harprit K. Singh, MA Candidate⁶; Mary Ellen Macdonald, PhD, Associate Professor⁷.

Feature Article: Marty C. M., Carter B. S. (2017, early online). Ethics and palliative care in the perinatal world, *Seminars in Fetal & Neonatal Medicine*. <http://dx.doi.org/10.1016/j.siny.2017.09.001>

This commentary brings together perspectives from an interdisciplinary group of researchers – five trainees, a research manager, and a senior scientist – who share an interest in the emergent field of childhood ethics⁸ and pediatric palliative care. In reviewing the November list of citations, we were especially drawn to Marty & Carter's paper which considers how advances in perinatal medicine have ushered in a range of new ethical challenges for families and clinicians. We chose this paper for our commentary because it reminds us that biomedical ethics is – and should be – a moving target. Keeping up with ethics in the perinatal world requires nuanced responses to the interrelation of ever-changing technologies and social values.

The paper is important for many reasons, three of which we will outline here. First, it clearly and succinctly highlights a range of compelling ethical issues that have arisen in perinatal care. We especially appreciated the authors' engagement with relational and narrative ethics frameworks which go beyond the more common use of principlism to acknowledge that the best interests of the fetus-newborn are "entwined and complicated" with those of the mother (and, we would add, other family members). Second, the paper outlines knowledge gaps and key ethical questions that urgently require the attention of pediatric palliative care researchers. A study might explore, for example, the ethical implications of not having evidence-based bereavement programs in place for families after a perinatal admission that resulted in the death of a fetus-newborn. A third reason this paper stands out is that the authors go beyond describing ethical challenges, to suggesting how clinicians can work with families to support shared decision-making and lessen suffering while also reflexively considering how their own values and beliefs are implicated in these discussions. Furthermore, they urge clinicians to advocate for practice changes, pointing to evidence that early integration of pediatric palliative care, including advance care planning, can positively impact perinatal care.



Citation lists are generated by [PedPaASCNET](#) through monthly searches of PubMed, Medline, and Embase. Visit our [blog](#) to see additional monthly commentaries on selected articles.

Certainly, the authors touch on issues that could be further unpacked. For example, while they point to the influence of clinicians' values and beliefs in perinatal practice, it is important to also acknowledge the embedded layers of social, structural, and institutional norms, values and beliefs that mediate how shared decision-making unfolds in practice. As well, the authors introduce the notion of 'mercy'; it would be helpful to consider how this principle should be differentiated from beneficence, and perhaps 'put to work' in providing an ethical foundation for transitioning from aggressive medical care to comfort measures. We found ourselves drawn to competing conceptualizations of the fetus-newborn as fundamentally embedded within a family unit while simultaneously a separate being with independent interests at stake. It is important to better understand how or whether clinicians reconcile these seemingly incompatible views as they navigate ethical challenges in the perinatal world. As more children are living with medical complexity, there is a pressing need for research examining the experiences of this group of children and their families, including research to understand the moral experiences (including but not limited to moral distress) of parents and clinicians in this context.

Marty and Carter's paper has potential to influence childhood ethics beyond the sphere of perinatal care. The principles and ethical issues discussed are certainly relevant in other pediatric contexts where parents', clinicians', and children's own perceptions of best interests are likely to vary. We suggest this paper would be an ideal choice for a journal club or a course in pediatric healthcare ethics as it includes valuable teaching points and is rich enough to elicit in-depth discussions and debates.

¹ CIHR Postdoctoral Fellow, VOICE (Views on Interdisciplinary Childhood Ethics), Centre for Research on Children and Families, McGill University

²David McCutcheon Doctoral Fellow in Pediatric Palliative Care, Ingram School of Nursing, McGill University

³School of Nursing, Faculty of Health Sciences, University of Ottawa

⁴David McCutcheon Postdoctoral Fellow in Pediatric Palliative Care, McGill University

⁵Montreal Children's Hospital of the McGill University Health Centre; Project Manager, VOICE (Views on Interdisciplinary Childhood Ethics), McGill University

⁶Specialization in Biomedical Ethics, Department of Philosophy/Biomedical Ethics Unit, McGill University

⁷Division of Oral Health and Society, Faculty of Dentistry, McGill University; Program Head, Pediatric Palliative Care Research, Montreal Children's Hospital of the McGill University Health Centre



Citation lists are generated by [PedPalASCNET](#) through monthly searches of PubMed, Medline, and Embase. Visit our [blog](#) to see additional monthly commentaries on selected articles.

⁸Carnevale, F. A., Campbell, A., Collin-Vézina, D., & Macdonald, M. E. (2015). Interdisciplinary studies of childhood ethics: developing a new field of inquiry. *Children & Society*, 29(6), 511-523