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Journal of Research in Nursing 2013 18: 469 originally published online 11 June 2013

DOI: 10.1177/1744987113491049

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Review: Neonatal palliative care in action: moving beyond the rhetoric and influencing policy

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Palliative care in infants and children is a small but developing area of specialised practice which differs significantly from adult palliative care in numerous ways. In the United Kingdom and across Europe, policy directives are being developed to enhance the delivery of care to infants and children requiring palliative care. Children's palliative care encompasses many aspects of care that are unique to children and advances are being made to improve care delivery to children (ACT, 2009a). In neonates specifically, as a subset of the paediatric population, it is recognised that while advances in neonatal medicine have improved the possibility of sustaining life, many infants still die within the neonatal period, making the requirement for the implementation of the principles of palliative care imperative. Yet it is often not provided (Moro et al., 2006) and many reasons are identified in the literature despite some significant advances having been made in care delivery and care pathway development (ACT, 2009b; Caitlin and Carter, 2002).

This paper is therefore timely and interesting in that it raises issues about developments in neonatal palliative care services. This paper offers an Australian perspective on the contemporary situation specifically related to neonatal palliative care but also identifies many of the dilemmas that can also apply in the delivery of palliative care to children generally. Despite support for neonatal palliative care by the World Health Organisation and other leading agencies, evidence exists that supports the inconsistency in the application of palliative care principles in this group. Challenges to the improved provision of care outlined in the paper include the philosophical and legal issues in treatment options and the ethical and practical challenges that can arise when caring for the newly born and infants in a neonatal unit. Important barriers to care provision have been identified. Many are already apparent in the literature used in the paper and some recommendations are made about how the situation can be improved.

Most of the recommendations are focussed on operational level strategies for implementation within individual neonatal units or individual sites. What is missing is the

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need for these complex ethical legal and health policy issues to be debated and addressed at strategic level by policy makers and fund holders. In addition to the education and management issues outlined, large multicentre studies, for example, are needed to identify best practice, outcome measures and an evidence base for practice. The need for local and national interprofessional debate and discussion also needs advanced. The authors identify some key issues related to the need to inform policy changes 'in moving a model of neonatal palliative care forward' and they do open the debate around some contemporary challenges that emerge when providing care for all infants who are facing the possibility of early death for any reason. The need for the development of a wholly collaborative interprofessional approach and partnership at all levels also warrants greater attention if the rhetoric surrounding care delivery for neonates is to be moved forwards at a strategic level in line with international developments and best practice.

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