

# Holistic care of a terminally-ill neonate in australia



In the Australian tertiary health care system, ‘ best practice’ in the care of a terminally-ill neonate and the neonate’s family centres on the provision of ‘ holistic care’. Neonates and their families are considered an interdependent system; therefore, holistic care involves the complete physical and psychological care of both the neonate and the family. However, quality holistic care can be challenging for nurses to achieve, particularly in a complex palliative model of care. This paper discusses the best practice holistic care of a terminally ill neonate and the neonate’s family in the context of the Australian tertiary health care system.

The term ‘ palliative care’ refers to the withholding and / or withdrawal of life sustaining treatment in patients with terminal illness, to prevent or relieve suffering and allow death to occur (World Health Organisation, 2015). In all patients, and children in particular, the World Health Organisation (2015: n. p.) highlights that palliative care must be a holistic process, one which provides “ active total care of the child’s body, mind and spirit, and [which] also involves giving support to the family”. Palliative care is concerned with providing a terminally ill neonate with the best conditions in which to live and with facilitating a comfortable death (Ahern, 2013; Bergstraesser, 2013). As parents are fundamental in the decision-making processes around neonatal palliation and as it is they who will be the most significantly affected by these decisions (Branchett & Stretton, 2012; Larcher, 2013), neonatal palliative care places a particular focus on caring for parents. There is consensus in the academic literature for palliation as the best model of care for neonates who are terminally ill; indeed, both the Australian College of Neonatal Nurses (2010) and the Royal Australian College of General

Practitioners (2014) highlight palliative care as a best-practice option for terminally ill neonates in the Australian context.

It is accepted that the parents of a terminally-ill neonate in palliative care require significant emotional support from neonatal nurses and other members of the health care team. Parents of palliated neonates often experience a complex emotional reaction to their situation, typically one of grief, shock and confusion (Badenhorst & Hughes, 2007; Gardner & Dickey, 2011). They may also experience feelings of profound loss, related not only to the impending loss of their child but also to a loss of their expectations, aspirations, role as parents and family dynamic, etc. (Gardner & Dickey, 2011). Additionally, it is not uncommon for parents to feel indecisiveness, shame or guilt about the decision to palliate their neonate (Reid et al., 2011), particularly when the outcome of the neonate's condition is uncertain. There is evidence from one early Australian study to suggest that women who experience neonatal loss have significantly higher rates of psychological distress and a greater risk of clinical depression than other mothers (Boyle et al., 1996). Thus, it is essential for neonatal nurses to validate the complex emotions the parents of a palliated neonate experience as being part of a normal and healthy psychological process (Badenhorst & Hughes, 2007). The provision of a clinical environment where parents' complex emotions can be expressed and explored is also important.

Best-practice models of neonatal palliative care recommend that parents take a lead role in the care of their infant, both in terms of decision-making and practical care (PSANZ, 2009; Australian College of Neonatal Nurses, 2010). Whilst some parents may resist providing care for and thus becoming

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attached to a palliated neonate, fearing that this will increase the degree and duration of their grief following the child's death, there is evidence to suggest this is not the case for many parents (Gardner & Dickey, 2011).

There is also evidence which indicates that many parents regret not spending more time with their deceased neonate, both prior to and following death (Williams et al., 2008). Thus, the literature recommends that parents should be treated by neonatal nurses as 'welcome partners' in the care of their baby (Griffin, 2013). Parents should also be encouraged and supported to be involved in the care of their baby to the extent that they feel comfortable doing so (PSANZ, 2009).

So that parents may be meaningfully and safely involved in the care of their palliated baby, it is important that neonatal nurses provide them with the information they require to make informed decisions – and this may begin in the palliation planning phase. Developing a flexible, transparent and family-centred palliation plan is essential, and so that their preferences are met, parents should take a key role in this process (Williamson et al., 2009). The palliation plan must focus on enabling 'open caregiving policies', highlight parents' wishes for their neonate and be legally documented (Breeze et al., 2007; Williamson et al., 2009; Gardner & Dickey, 2011). Whilst most parents wish to be involved in decisions and planning around end-of-life care for their neonate, they may find this responsibility overwhelming (Williams et al., 2008). Parents will be exposed to a range of options and opinions which they must synthesise in order to make the best decisions for their family; however, it is important for neonatal nurses to realise that highly emotive situations can often cause significant deficits in parents' ability to

comprehend and process such information (Williams et al., 2008). Evidence suggests that repetition printed literature is important in the provision of information to parents in situations involving neonatal death (PSANZ, 2009). The timing and delivery of the information provided by neonatal nurses should also be carefully planned to ensure maximal uptake (PSANZ, 2009).

Australian guidelines recommend that when supporting the parents of a palliated neonate, neonatal nurses focus on the normalcy of parenthood wherever possible (PSANZ, 2009). Neonatal nurses should assist parents to engage in normal parenting opportunities - including holding, changing and bathing their baby, and routine interactions such as reading cues and providing comfort - if they feel able to do so (PSANZ, 2009). For babies with longer palliative periods and where the baby's condition permits, feeding - including breastfeeding or the feeding of expressed breast milk - is also an important consideration. Normal rituals associated with infancy, such as naming ceremonies and baptism, should also be followed if the family consider these to be important (PSANZ, 2009; Weidner et al., 2011).

A palliated neonate's relationship with extended family may also be an important consideration for many families. Though visiting in intensive care nurseries is often restricted to parents, photographs and videos of the baby may be shared with extended family members and these relatives may be encouraged to send toys, clothing and nursery decorations, etc. for the baby in return (PSANZ, 2009). Research suggests that the support of family is a significant factor in the recovery of parents from the death of a neonate; indeed, the grief of parents may be enhanced when there is a lack of familial engagement with a palliated neonate (Gardner & Dickey, 2011). Grief of the

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family itself is also essential to consider; for example, there is evidence to suggest that better outcomes are achieved when grandparents and siblings are engaged with parents in the process of bereaving a deceased neonate (Roose & Blanford, 2011).

The literature suggests that the creation of tangible memories is fundamentally important to the parents of a palliated neonate, and this is included as a recommendation in Australian perinatal mortality guidelines (Capitulo, 2005; PSANZ, 2009). Memories collected may include photographs and videos, prints or casts of the hands and feet, locks of hair, identification bracelets or cards, toys and gifts, nursery decorations, and blankets, hats or clothing, etc. (De Lisle-Porter & Podruchny, 2009; PSANZ, 2009). It is important to note that many parents, and particularly those in denial of their baby's palliative state, may resist collecting such memories; in this case, it is recommended that hospitals do so and hold these with the baby's clinical documentation until such time as the family is ready to receive them (PSANZ, 2009).

So that parents may maximise the quality time they spend with their neonate, it is important for neonatal nurses consider the wider social factors which may affect them and their families (Ahern, 2013). Issues related to finances, employment commitments, accommodation, transport and the care of other children should be referred to a hospital social worker. Where required, postnatal medical attention in a clinical area where the mother will not be in close proximity to other healthy neonates, in addition to the suppression of lactation, are important (Badenhorst & Hughes, 2007). The environment in which the palliative care takes place must also be

considered; Australian guidelines suggest that this environment should be private, comfortable, peaceful and supportive (Kain, 2006; PSANZ, 2009).

Once the decision has been made to palliate a neonate, all treatment which is not essential to the baby's comfort must be withheld and withdrawn. This includes removing all inessential intravenous lines, invasive ventilation, monitors and pharmaceutical treatment. As the neonate begins to decline physiologically and the activity of the gastrointestinal system reduces, nasogastric feeding and hydration should also be ceased (Porta & Frader, 2007). Administering an appropriate dose of narcotic analgesia to relieve discomfort and sedate the respiratory drive may be useful (Williams et al., 2008; Carter & Jones, 2013); however, parents should be assured that this does not constitute euthanasia, which is illegal in Australia. At this stage, the end-of-life rituals should be conducted according to parental preference (Ahern, 2013). As the neonate progressively declines, it is essential that neonatal nurses prepare parents with information about how the baby's death will likely occur. This includes the possibility of the neonate rapidly decompensating and displaying distressing signs such as hypoxic agitation, gasping, intercostal recession, pallour and temperature loss (Brosig et al., 2007; Williams et al., 2008; Carter & Jones, 2013). Information provided should also include the fact that timing to death cannot be predicted (Williams et al., 2008). Parents should be given a choice as to whether they remain with the neonate during death.

Following death, parents should be provided with the opportunity to hold, change or bathe their baby if they wish to do so (PSANZ, 2009). Whilst many parents are reluctant to or even fear engaging with their deceased baby,

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there is evidence to suggest that no parent regrets this experience and that many find it valuable (Capitulo, 2005). The policies of most maternity services in Australia allow parents to view their neonate as many times they wish, and some may also provide parents with the option of taking the baby home for a short period (PSANZ, 2009). Once the parents are ready, neonatal nurses should assist them to complete death registration and autopsy documents, as appropriate. Nurses should also support parents to organise a funeral through a company of their choice; in Australia, a funeral is legally required for all neonates born at or over 20 weeks gestation. A funeral is particularly important for many parents in terms of achieving closure (Williams et al., 2008).

Most literature recommends that the parents who have experienced a neonatal death receive 'early supported discharge' from hospital (Gardner & Dickey, 2011). Referral to support services in the parents' own community - including general practitioners, counsellors and peer support groups, etc. - are essential considerations. Follow-up is also important; for example, if an autopsy was performed, neonatal nurses should communicate these results to parents in a timely manner (PSANZ, 2009; Reid et al., 2011). Additionally, many parents find personal follow-up, including telephone calls and cards, from the neonatal nurses who cared for their baby to be meaningful (Weidner et al., 2011), reinforcing that their child was important and will be remembered.

In the Australian tertiary health care system, 'best practice' in the care of a terminally-ill neonate and the neonate's family centres on the provision of 'holistic care'. As they are an interdependent system, holistic care involves

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the complete physical and psychological care of both the neonate and the family. This paper has discussed the best practice holistic care of a terminally ill neonate and the neonate's family in the context of the Australian tertiary health care system. It has demonstrated that whilst holistic care may be challenging to achieve, it is essential in delivering the best positive outcomes in a complex situation such as neonatal palliation.

## References

Ahern, K., (2013), ' What neonatal intensive care nurses need to know about neonatal palliative care', *Advances in Neonatal Care*, vol. 13, no. 2, pp. 108-114.

Australian College of Neonatal Nurses 2010, *Palliative Care in the Neonatal Nursery: Guidelines for Neonatal Nurses in Australia*, viewed 04 October 2015, <https://acnn.sslsvc.com/acnn-resources/clinical-guidelines/G3-Palliative-care-in-the-neonatal-nursery.pdf>

Badenhorst, W., & Hughes, P., (2007), ' Psychological aspects of perinatal loss', *Clinical Obstetrics & Gynaecology*, vol. 21, no. 2, pp. 249-259.

Bergstraesser, E., (2013), ' Pediatric palliative care: When quality of life becomes the main focus of treatment', *European Journal of Pediatrics*, vol. 172, no. 2, pp. 139-115.

Boyle, FM., Vance, JC., Najman, JM., & Thearle, JM., (1996), ' The mental health impact of stillbirth, neonatal death or SIDS: Prevalence and patterns of distress among mothers', *Social Science & Medicine*, vol. 43, no. 8, pp. 1273-1282.

<https://assignbuster.com/holistic-care-of-a-terminally-ill-neonate-in-australia/>

Branchett, K., & Stretton, J., (2012), ' Neonatal palliative and end of life care: What parents want from professionals', *Journal of Neonatal Nursing*, vol. 18, no. 2, pp. 40-44.

Breeze, ACG., Lees, CC., Kumar, A., Missfelder-Lobos, HH., & Murdoch, EM., (2007), ' Palliative care for prenatally diagnosed lethal fetal abnormality', *Archives of Disease in Childhood*, vol. 92, no. 1, pp. 56-58.

Brosig, CL., Pierucci, RL., Kupst, MJ., & Leuthner, SR., (2007), ' Infant end-of-life care: The parents' perspective', *Journal of Perinatology*, vol. 27, no. 510-516.

Capitulo, KL., (2005), ' Evidence for healing interventions with perinatal bereavement', *The American Journal of Maternal Child Nursing*, vol. 30, no. 6, pp. 389-396.

Carter, BS., & Jones, PM., (2013), ' Evidence-based comfort care for neonates towards the end of life', *Seminars in Fetal & Neonatal Medicine*, vol. 18, no. 2, pp. 88-92.

De Lisle-Porter, M., & Podruchny, AM., (2009), ' The dying neonate: Family-centred end-of-life care', *Neonatal Network*, vol. 28, no. 2, pp. 75-83.

Gardner, SL., & Dickey, LA., (2011), *Grief and Perinatal Loss*, in SL Gardner, BS Carter, M Enzman-Hones & JA Hernandez (eds.), *Merenstein & Gardner's Handbook of Neonatal Intensive care*, Australian Academic Press, Queensland.

Griffin, T., (2013), ' A family-centred ' visitation' policy in the neonatal intensive care unit that welcomes parents as partners', *The Journal of Perinatal & Neonatal Nursing*, vol. 27, no. 2, pp. 160-165.

Kain, VJ., (2006), ' Palliative care delivery in the NICU: What barriers to neonatal nurses face?', *Neonatal Network*, vol. 25, no. 6, pp. 387-392.

Larcher, V., (2013), ' Ethical considerations in neonatal end-of-life care', *Seminars in Fetal & Neonatal Medicine*, vol. 18, no. 2, pp. 105-110.

Perinatal Society of Australia and New Zealand (PSANZ) 2009, Clinical Practice Guideline for Perinatal Mortality, viewed 04 October 2015, [http://www.stillbirthalliance.org.au/doc/Section\\_1\\_Version\\_2.2\\_April\\_2009.pdf](http://www.stillbirthalliance.org.au/doc/Section_1_Version_2.2_April_2009.pdf)

Porta, N., & Frader, J., (2007), ' Withholding hydration and nutrition in newborns', *Theoretical Medicine & Bioethics*, vol. 28, no. 5, pp. 443-451.

Reid, S., Bredemeyer, S., van den Berg, C., Cresp, T., Martin, T., Miara, N., Coombs, S., Heaton, M., Pussell, K., & Wooderson, S., (2011), ' Palliative care in the neonatal nursery', *Neonatal, Paediatric & Child Health Nursing*, vol. 14, no. 2, pp. 2-8.

Roose, RE., & Blanford, CR., (2011), ' Perinatal grief and support spans the generations: Parents' and grandparents' evaluations of an intergenerational perinatal bereavement program', *Journal of Perinatal & Neonatal Nursing*, vol. 25, no. 1, pp. 77-85.

Royal Australian College of General Practitioners 2014, Paediatric Palliative Care: The Role of the GP, viewed 04 October 2015, <http://www.racgp.org.au/afp/2014/april/paediatric-palliative-care/>

Weidner, NJ., Cameron, M., Rebecca, C., McBride, J., Mathias, EJ., & Byczkowski, TL., (2011), ' End-of-life care for the dying child: What matters most to parents', *Journal of Palliative Care*, vol. 27, no. 4, pp. 279-286.

Williams, C., Munson, D., Zupancic, J., & Kirpalani, H., (2008), ' Supporting bereaved parents: Practical steps in providing compassionate perinatal and neonatal end-of-life care', *Seminars in Fetal and Neonatal Medicine*, vol. 13, no. 5, pp. 335-340.

Williamson, A., Devereux, C., & Shirtliffe, J., (2009), ' Development of a care pathway for babies being discharged from a level 3 neonatal intensive care unit to a community setting for end-of-life care', *Journal of Neonatal Nursing*, vol. 15, no. 5, pp. 164-168.

World Health Organisation 2015, WHO Definition of Palliative Care, viewed 04 October 2015, <http://www.who.int/cancer/palliative/definition/en/>