

Neonatal palliative care in action



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This theoretically focused paper aims to move beyond the rhetoric of espousing the importance and timeliness of a model of palliative care for the neonatal population, to explore how what is known already can influence health and social policy. While this paper is largely informed by current events at Senate level within Australian Government, the research – empirical and otherwise – and the strong societal voice that informs the need to move the neonatal palliative care agenda forward transects borders and nations and therefore has relevance to all westernised countries.

In recent years, there has been increasing awareness regarding the need for evidence-based neonatal palliative care, yet despite literature supporting neonatal palliative care practice, and the availability of protocols to inform practice, neonatal palliative care in the clinical environment remains extemporized.

A recent Commonwealth of Australia Senate enquiry into palliative care in Australia (Wilkinson et al., 2012) invited a submission regarding neonatal palliative care, bringing this widely neglected aspect of neonatal care to the forefront for the first time in our country.

In recent years, palliative care for the neonatal population has become increasingly topical and part of the lexicon of contemporary neonatal nursing practice. An evidence-based protocol (Catlin & Carter, 2002) has been available for a decade to inform this model of care, yet in reality, provision of palliative care to newborns is ad hoc (Cignacco & Zeitschrift-Für, 2004; Maginnes, 2002), and components of this protocol have been difficult to implement. The reasons why engaging in a palliative model of care were

unclear, but now the barriers to a neonatal palliative model of care have been well defined to the point where this knowledge can inform policy (Kain, 2011; Kain et al., 2009).

Babies die too

At a societal level, death and dying in infancy is driven by high emotional content because the death of a newborn is considered a life that has ended too soon: illness and death are unexpected for a newborn and are devastating and life-altering events for the family. Society in general does not know how to respond to the death of a newborn, and therefore have few established social norms to help a family cope with such loss. Society more readily accepts deaths of adults and even of children. Complicating these ethical concerns is the notion that the death of a newborn in this highly curative environment is a failure of medical science.. Whilst this highly technical environment saves the lives of newborns, healthcare needs to provide for the needs of newborns who will die before they leave the hospital. Due to a lack of coordinated interdisciplinary services, dying children are often deprived of the benefits of palliative care (Carter et al., 2004), yet evidence of an increasing societal demand for palliative care provision to the neonatal population is reported in the literature (Maginnes, 2002; Romesberg, 2003; Conway and Moloney-Harmon, 2004).

This paper concerns itself with the sobering fact that babies die too, however. Newborns and infants have the highest death rate in the paediatric population (Pierucci et al., 2001). In Australia, 4 out of every 1, 000 infants die before their first birthday (Australian Bureau of Statistics, 2011). This is equal to almost 1, 200 deaths across Australia each year. In the United

Kingdom in 2010, the infant mortality rate was 4.3 deaths per 1,000 live births. For very low birth-weight babies (under 1,500 grams) and low birth-weight babies (under 2,500 grams), mortality rates were 164.9 and 36.8 deaths per 1,000 live births respectively (Office for National Statistics, 2010). In United States data from 2009, the infant mortality rate was higher, with 6.39 deaths per 1,000 live births (Centers for Disease Control and Prevention, 2011). These epidemiological data highlight that even in developed countries, infancy remains one of the most dangerous periods of human life, and according to one source, the death rate in the first year of life is only exceeded by those over the age of 55 (Maternal Perinatal and Infant Mortality Committee, 2011).

According to the data sources above, the infant mortality rates are marginally decreasing. However, increasing survival rates are balanced by increasing morbidity issues. Since the escalation of technology and medical advances – including antenatal corticosteroids and postnatal surfactant treatment (Walther, 2005) – treatment options for newborn infants have increased, thus enabling healthcare professionals to provide care to newborns who previously would not have been intubated, or were presumed to be dying (Pierucci et al., 2001). Advances in life-sustaining medical technology present ethical concerns with a strong emotional component, including when it is appropriate to withhold or withdraw intensive care therapies (Walther, 2005). Advances in neonatal medicine have resulted in the survival of extremely preterm infants previously considered non-viable. To summarise, despite technological advances, increases in the margins of viability, and highly skilled healthcare delivery, some newborns will still die

in the neonatal intensive care unit [NICU], often as a result of extreme prematurity and other complex medical problems (Yam et al., 2001).

Neonatal palliative care in context

To engage in objective and balanced discussion, it is first necessary to address the assumption that palliative care is inherently beneficial for all patient populations who may require it. Some literature offers a critique of the palliative approach, arguing that the emphasis of palliative care should not be on extinguishing the denial of death but on the relief of suffering (Zimmermann, 2004). Such philosophical debate argues that the palliative approach may result in the ‘social death’ of a person before their actual death. This results in the ideal of ‘living until you die’ being unfulfilled (McKechnie et al., 2007). McKechnie et al (2007) argue that whether a dying person experiences a ‘good death’ or not is determined not only by the management of the dying process by health professionals, but also by the way in which the dying person is perceived by others. The palliative approach may be interpreted as being somewhat prescriptive, yet there are no guidelines for the dying role; everybody dies differently and individually (McKechnie et al., 2007). Such debate suggests that healthcare professionals should be mindful of the palliative approach leading to the ‘social death’ of a dying baby prior to its actual, physical death.

In context, neonatal palliative care involves active treatment aiming to ensure that newborns receive care in a comfortable environment, free from pain and distressing symptoms, with emotional and practical support for both parents, and healthcare professionals. When the decision to withhold resuscitation, discontinue resuscitation, or forgo other life-supporting

treatments are made, compassion for the family and their needs become paramount. This humane and compassionate care should include careful handling of the newborn, maintaining warmth, avoiding invasive procedures, and unobtrusive monitoring.

Moving beyond rhetoric: the difficulties

Death is a part of life in any NICU, and any healthcare service provider associated with labour and delivery and the care of newborns would inevitably experience perinatal death and bereavement (Leuthner, 2004). Furthermore, there is a neonatal population that would benefit from this model of care, recognised under three broad categories: newborns born at the limits of viability; newborns born with a lethal anomaly and/or malformation; and newborns who have received intensive care in the NICU but for whom this model of care has become inappropriate. These categories of newborns have low rates of survival and high morbidity on the occasions that they do survive, and palliative care may be the best approach (Carter, 2004).

Despite this, palliative care principles are difficult to apply to neonatology. The social stigma of denying neonatal death coupled with the paradox of providing palliative care in a curative setting present a compelling research problem. However, it is possible for palliative care to coexist with curative treatment modes because palliative care has become an area of expertise within many other health disciplines, such as in adult intensive care. Yet, advances in palliative care have not yet been integrated effectively into standard paediatric/adolescent clinical practice, and even less so into neonatal clinical practice. Therefore, the precepts of palliation should be a

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basic component of the attitudes, knowledge base and practice skills of all health care professionals (National Association of Neonatal Nurses www.nann.org, 2005). The previous section suggests that the clinical application of palliative care should be seemingly straightforward. However, when one explores these clinical ideologies in the context of contemporary neonatology, the notion of neonatal palliative care raises a myriad of issues and controversies.

Whilst it is noted that there have been remarkable achievements in newborn survival and these advances have increased the possibility of sustaining life, this paper has highlighted that more newborns die in the neonatal period than at any other time in childhood. Despite this, there is much that is unknown about both the needs and the care of these critically ill newborns (Field and Behrman, 2003). To illustrate, 34% of all childhood deaths occur within the neonatal period (Carter, 2004). It would be a reasonable assumption, then, that when death becomes inevitable for a marginally viable and critically ill newborn, that decisions to prolong suffering be reassessed and a transition to palliative care at least be considered (Carter, 2004). Again, such a rationale is not straightforward. This notion necessitates that aggressive, curative treatment be withheld, or withdrawn: yet how does this translate into actual practise. When is it appropriate to withhold or withdraw curative care and, in doing so, what are the needs of the dying newborn, the family, and the staff to provide a humane and compassionate death. The literature suggests that confusion exists about what palliative care constitutes, and when – if ever – it is appropriate to withhold aggressive, curative care. In Catlin's (1999) research of neonatologists'

resuscitation practices of extremely low-birth weight (ELBW) preterm newborns, one fourth of participants stated that withholding resuscitation attempts wasn't an option for them. Emotive terms such as 'executing', 'killing' and 'pulling the trigger' were used to describe the practice of 'doing nothing' (Catlin, 1999: p 271). Attempting resuscitation even on the smallest ELBW fetal-newborns was described as a neutral action for which they were simply trained to do: there was no training in terms of when 'not to do'. One neonatologist recalled: 'there's no one telling you the rules, because there aren't any rules' (Catlin, 1999: p 271).

There is often difficulty in accepting a palliative model of care in contemporary healthcare. There is a focus upon curative treatment regimens, with a drive to offer aggressive interventions. This may be because the serious nature of disease is still evolving or perhaps to postpone the acceptance that death has become inevitable. Healthcare needs to consider when no potentially curative intervention exists, or their benefits have become exhausted. This can lead to a feeling of hopelessness that there is nothing left to offer the newborn (Craig and Goldman, 2003). There is a notion of curing at all costs, and it is stated that in acute care settings the purpose of treatment is generally to cure, and it is for this reason that facing the death of a patient and providing palliative care can be 'uncomfortable', and engender a sense of failure (Davies et al., 1996; Hartline, 2002; Lo et al., 1999).

In some countries, such as the Netherlands (Moro et al., 2006), euthanasia of certain newborns is considered a viable option for marginally viable and critically ill newborns in countries. Discreetly practiced active euthanasia,
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although technically illegal, has been tolerated in countries such as the Netherlands for over 30 years. There is no mention in the law of active euthanasia for newborns and small children, which remains illegal. However, in the Netherlands neonatal and infant deaths preceded by the deliberate administration of life reducing medication are known to take place, although infrequently (Cuttini et al., 2004). This paper does not seek to advocate or condemn such practices, however in order to locate palliative care in contemporary neonatal care, such discussion is necessary.

In a study by Provoost and Cools (2005) a death-certificate audit was performed for all deaths of newborns and infants in Flanders over a 12-month period. With a response rate of 253 (87%), 121 (69%) of the 175 neonatologists also responded to a series of attitude questions. An end-of-life decision was possible in 194 of the 253 deaths studied, and such a decision was made in 143 cases. Lethal drugs had been administered in 15 cases among 117 early neonatal deaths and in two cases among 77 later deaths. Furthermore, the attitude study demonstrated that 95 of the 121 neonatologists reported that their professional duty at times included the prevention of unnecessary suffering by hastening death and 69 of 120 supported legalization of life termination in some cases. This research reported that within its sampling frame, the majority of neonatologists favored the legalization of the use of lethal drugs in certain cases.

The EURONIC study (Arlettaz et al., 2005) demonstrated that the administration of lethal drugs with the aim of terminating life was reported in the Netherlands and France, in contrast to other European countries. This report reasoned that the prevention of suffering at times justifiably

demanded the use of lethal drugs and that non-treatment unnecessarily prolonged suffering. The study found that most of the neonatologists participating in the research supported a change in the law, permitting the termination of life (Provoost and Cools, 2005). However, these guidelines, known as the Groningen Protocol, relate to newborns who would continue to survive after the withdrawal of medical care. Under the auspices of such a protocol, the decision to terminate the life of a newborn is based upon perceived intractable suffering (Verhagen and Sauer, 2005) and in this decision-making process, the prognosis, the expected outcome of treatment in terms of quality of life, and the burden placed on the patient by the treatment (pain, discomfort and physical limitation) play an equal role (Arlettaz et al., 2005).

In summary, intensive care can be an unpleasant, uncomfortable experience for newborns even when it is appropriate. As stated by Yu (2005) a 'proactive policy to initiate intensive care must take into consideration that a decision to withdraw intensive care might have to be made in selective newborns at a later stage in the course of the newborn's treatment. In the event that the newborn's subsequent clinical course indicates that further curative efforts are futile or lack compensating benefit, intensive care should be discontinued and palliative care, which provides symptomatic relief and comfort, should be introduced' (Yu, 2005: p 746 – 747).

Given this, the initiation or continuation of treatment which is considered futile is unlikely to be in the best interests of the newborn. Even so, many healthcare professionals find it difficult to accept that palliative care may be a more appropriate course of action (Craig and Goldman, 2003). The NICU

environment has changed dramatically in past decades and continues to do so into the new millennium, with advances in technology and prenatal screening. These advances mean that many newborns who might once have died are now surviving (Handley, 2003). Therefore, the concept of providing palliative care to newborns is an emerging one, but as argued, it is a concept that is proving difficult to incorporate into contemporary neonatal care.

How can what is known already influence policy?

To inform policy on any level, it is imperative that health professionals in the NICU are knowledgeable about legislative priorities and any public concerns regarding palliative care for neonates. There are several priorities for moving this model of care forwards, which include legislation that supports access to care such as development and funding support of perinatal hospices, continuity of care, caregiver support, research and in particular education for the healthcare professionals caring for dying babies and their families.

It is remiss to overlook that neonatal palliative care is emotionally and ethically laden: When considering moving this model of care forward from an evidence base, it is useful to remember that health care requires that practitioners speak in ‘two different languages-the language of science with its quantifiable outcomes . . . as well as the language of people’ (Leight, 2002: p. 109).

The strong societal voice is at the epicentre of social care policy when considering palliative care models for the neonatal population. Opinion in the literature suggests that society perceives medicine as entering an age of ‘miracles’ and ‘wonder’, and this is all upon public display in the NICU (Levy

Guyer, 2006; Tisdale, 2003). Given these influences, parents often have unrealistic expectations with what can be offered to their child in terms of medical intervention. This may lead to the belief in the ‘medical miracle’ to explain a technological solution for everything (Levy Guyer, 2006; Paris, DeLisser, & Savani, 2000). Extremely premature newborns have survived, and so there is an unsound basis for parental requests that everything possible be done to ‘save’ their babies. Due to reports of these so-called ‘miracle babies’ (The Age., 2007) the public may expect more from the NICU now that some newborns born at 22 weeks gestation have survived. It is expected that modern medicine can save every newborn born beyond this milestone (Levy Guyer, 2006; Paris et al., 2000).

To summarise, policy directives in the area of caring for marginally viable and critically ill newborns needs to be conversant across the multiple paradigms and perspectives that inform this area of neonatal practice. This includes an understanding of the psychological, social, cultural, ethical and political dimensions of caring for marginally viable and critically ill newborns. This approach generates breadth of knowledge and a depth of understanding of both nursing and societal perspectives of caring for these babies. The discourse of these perspectives makes an important contribution to the development of our knowledge about palliative care in a neonatal context. As described, the context of providing care to marginally viable and critically ill newborns is emotive, and controversial. Regardless of decisions made on behalf of these newborns, and by whom, there are a myriad of stakeholders affected by these decisions. Ultimately, these stakeholders are represented within society as parents and families, and are buoyed, influenced and even

encumbered by the greater influences of societal mores, public opinion and the media.

Conclusions

Changes in societal attitudes and models of care are necessary to achieve any real gain in quality end-of-life care for any population (Field and Cassel, 1997), and this is perhaps the most challenging aspect of moving palliative care forward as an international agenda for dying babies. This paper has referred to the education, research initiatives, that potentially could contribute to a stronger social consensus regarding this model of care.

Health care professionals in the NICU need to continue to strive to improve care for those who are most vulnerable in society, in this context dying babies and their families. Healthcare professionals and policymakers need to work together to make a difference in the lives of the babies they care for who are approaching the end of life.

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Conflict of interest statement

None declared.

Key points

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