

# Perinatal palliative care: a developing specialty

Rut Kiman, Lara Doumic

**P**aediatric palliative care is younger than its adult counterpart. A few paediatricians were beginning to create the specialty of neonatology as early as the 1950s, but it was not until the late 1970s that nurses, GPs, and paediatricians acknowledged that children facing death have specific needs and that hospitals might not be the best places to meet those needs. Many models of paediatric palliative care have evolved since then. Jonathan Whitfield and William Silverman initiated the application of hospice concepts to neonatal care in 1982, and following that neonatal and perinatal medicine have greatly developed (Silverman, 1982; Whitfield et al, 1982). Key issues in the development of this specialty have been the use of the Apgar score; thermoregulation; nutrition; artificial ventilation; management of perinatal hypoxic–ischaemic brain injury and respiratory distress syndrome; advances in neonatal surgery; and the evolution of neonatal nursing as a subspecialty (Whitfield et al, 2004).

Neonates and babies have the highest death rate in the paediatric population (Save the Children, 2013). Globally, since 1970, the number of children dying annually has declined by more than half, even though the population has almost doubled. However, 3 million newborns still die each year, making up nearly half of the world's under-5 child deaths.

The three main causes of neonatal death are complications during birth, prematurity, and infections. More than 1 million babies die on the first day of life, making the birth day the most dangerous day for babies in nearly every country, rich and poor alike (Save the Children, 2013). Countries across all income levels have made progress in reducing newborn mortality, but the gap between rich and poor has widened, with high-income countries achieving the fastest reductions. Almost 98% of newborn deaths occur in developing countries, and nearly two-thirds occur in just ten countries: India, Nigeria, Pakistan, China, DR Congo, Ethiopia, Bangladesh,

## Abstract

Neonates and babies have the highest death rate in the paediatric population. Perinatal palliative care aims to enhance the quality of life of babies with a life-limiting condition and their families. However, very little data is available on perinatal palliative care and its impact on babies and families along their journey. End-of-life decision-making for babies with an adverse prognosis also remains ethically challenging. This paper provides an overview of perinatal palliative care and its development, and then considers some of the issues affecting this field by looking at single national, institutional, and patient case studies.

**Key words:** End-of-life care ● Perinatal palliative care ● Neonatal palliative care ● Newborn ● Hospice

Indonesia, Afganistan, and Tanzania (Save the Children, 2013).

Perinatal palliative care aims to enhance the quality of life of babies with a life-limiting condition and their families. However, very little data is available on perinatal palliative care and its impact on babies and families along their journey. This paper provides an overview of perinatal palliative care and its development, and then considers some of the issues affecting this field by looking at single national, institutional, and patient case studies.

## What is perinatal palliative care?

Palliative care principles can be applied in the neonatal intensive care unit (NICU), where they can be integrated into patient and family care plans regardless of whether the treatment goal is providing a cure, prolonging life, or exclusively palliation and comfort until an expected death (Carter, 2004). Together for Short Lives (2009), a UK association for children's palliative care, defined paediatric palliative care as follows:

**'Palliative care for a foetus, neonate, or infant with a life-limiting condition is an active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, at**

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the time of death and beyond. It embraces physical, emotional, social, and spiritual elements and focuses on the enhancement of quality of life for the neonatal infant and support for the family. It includes the management of distressing symptoms, the provision of short breaks, and care through death and bereavement.’

Perinatal palliative care can support those families who are notified prenatally that the foetus being carried has a potentially lethal anomaly. The perinatal hospice has been offered as an alternative to pregnancy termination for a non-viable foetus. Despite advances in foetal detection of congenital anomalies, various factors, including lack of prenatal care, may lead to the delivery of an infant with an unexpected anomaly that may prove to be lethal. Planning for future decision-making is the essence of prenatal palliative care, which includes choosing who will deliver the baby, where the delivery will take place, and who will be present; notifying all members of the obstetric and neonatal team that palliative care will be offered; delineating the resuscitation status; planning for comfort measures immediately at birth; having medications on hand to treat symptoms buccally if intravenous access is not available; deciding which diagnostic interventions, if any, will be performed; arranging for spiritual/cultural care; and planning for family support.

### Which babies are eligible?

Palliative care is recommended for babies born at an extremely low birth weight (1 lb or less), before 23 weeks of gestation, or with an abnormality or malformation incompatible with life, and for those who will experience more burden than benefit from further treatments for their condition. Discussions with families in the prenatal and perinatal period should revolve around the diagnosis and prognosis and the degree of certainty around both. Further, as stated by Leuthner (2004), the meaning of the prognosis should be considered, along with appropriate consultation with the neonatologist, neurologist, and/or cardiothoracic surgeon, depending on the condition. Around the world, most neonatal deaths occur in hospital settings; generally, few parents are allowed to take their babies home to die with appropriate support or to a children’s hospice (Penn et al, 2013).

End-of-life decision-making for newborns with an adverse prognosis is ethically challenging. Physicians aim to cure disease when possible, but also need to recognise the limits of treatment and accept when death is inevitable. However,

developments in medical technology have changed when, where, and how we die. Issues around when to stop attempting curative treatment in neonatology have been much discussed since the 1990s (Silverman, 1992; American Academy of Pediatrics Committee on Fetus and Newborn, 1995; Rebagliato et al, 2000; Carter and Bhatia, 2001; Leuthner and Pierucci, 2001).

The survival rates of extremely preterm infants and extremely low-birthweight infants have improved over the years, as a result of better prenatal and neonatal care—mainly greater use of antenatal steroids, appropriate management in the delivery room and in the initial care, use of surfactant therapy, and better modalities of assisted ventilation (Whitfield et al, 2004). However, this improvement in survival has not been associated with an equal reduction in morbidity. Research by Marlow et al (2005) showed that children born at less than 26 weeks of gestation are more likely to have cognitive sequelae than more mature preterm populations. In fact, the frequency of bronchopulmonary dysplasia, sepsis, poor growth, and neurological disorders may be increasing (Sebastiani and Ceriani Cernadas, 2008).

Each country, and perhaps every centre, should base its treatment decisions on its survival and morbidity rates and the quality of the child’s life. Palliative care is as important as intensive care interventions as it can ensure that the baby has the best quality of life for however long it lives. Decisions should also be based on the availability of resources for neonatal care and support after discharge. Neonatal palliative care guidelines encourage professionals to consider palliative care as an appropriate addition or alternative to curative treatment (Caitlin and Carter, 2002; Together for Short Lives, 2009; British Association for Perinatal Medicine, 2010; Tejedor Torres et al, 2012).

### Palliative care in perinatal settings

Despite the interest in palliative care in perinatal medicine, there have been no evidence-based empirical studies to indicate the best model of care for this clinical setting. Perinatal palliative care includes, among other things, the idea of comprehensive care, and early and integrative care initiated antenatally. Balaguer et al (2012) found that paediatric palliative has evolved to incorporate some of the same aspects as general newborn care.

The initial physical care provided, such as pain relief and comfort, is immediately supplemented with maternal bonding and consideration of other emotional aspects. The importance of family participation in the NICU, which found

expression in the concept of ‘family-centred care’ in the 1960s and 1970s, also seems to have influenced neonatal palliative care. Recently, attention has been drawn to the need for ‘integrative care’. Milstein (2005) highlighted the importance of introducing healing and palliation as an integrative paradigm of care, when indicated, alongside curative measures as soon as any diagnosis, especially a critical one, is made. He also pointed out that, because loss can be experienced in many conditions, even in the absence of death, bereavement can be an ongoing, continual process throughout the disease course. In this paradigm, healing and bereavement are facilitated with a mindset of ‘being with’, while curing is facilitated with the usual mindset of ‘doing to’ (Milstein, 2005).

### National case study: infant mortality in Argentina

For centuries, communicable diseases were the main causes of death around the world. Life expectancy was often limited by uncontrolled epidemics. After the Second World War, with medical research achievements in vaccination, antibiotics, and public health, non-communicable diseases (NCDs) became increasingly significant in industrialised countries. NCDs are now also an enormous challenge for developing countries, where demographic and socioeconomic transitions impose more constraints on dealing with the double burden of infectious and non-infectious diseases. It is predicted that, by 2020, NCDs will cause seven out of every ten deaths in developing countries. Paediatric palliative care has an important role in tackling NCDs (Jakab, 2011; The NCD Alliance, 2011; World Health Organization, 2012).

According to UNICEF (2013), infant mortality decreased by 54% between 1990 and 2001 in Argentina, comprising falls in both neonatal mortality (up to 28 days) of 51.4% and in post-neonatal mortality of 56.1%. In the following decade (2001–2010), there was a further 27% decrease (Table 1). The last measurement in 2012 indicated that the average mortality in the country for babies aged less than 1 year was 11.1 per 1000 live births. However, there are large disparities in the risk of death for children living in different regions of Argentina. For example, in Formosa in the north east, 21.2 children aged under 1 year die per 1000 live births, whereas in central Buenos Aires the figure is 11.8, and in the most southern province of Tierra del Fuego it is 7.1 (UNICEF, 2013).

Survival of babies weighing less than 1.5 kg at birth improved in the past decade and noticeably

**Table 1. Infant mortality in Argentina**

Year	Mortality rate*
2002	16.8
2003	16.5
2004	14.4
2005	13.3
2006	12.9
2007	13.3
2008	12.5
2009	12.1
2010	11.9
2011	11.7
2012	11.1

\*Deaths among babies aged <1 year per 1000 live births

between 2010 and 2011, when the estimated survival rate increased to 64% from 61%. However, the survival rate for these babies in Argentina is still far from the international standards (Marshall et al, 2005). In very few institutions does survival reach or exceed 90% (WHO, 2012). The worldwide mean for the proportion of premature births is 11% of total births, whereas in Argentina 8% of babies are born prematurely, which translates to 60 000 babies each year (Ministerio de Salud Presidencia de la Nacion, 2012; UNICEF Argentina, 2013). However, this proportion is increasing (UNICEF, 2013).

### Institutional case study: Hospital Nacional ‘Profesor Alejandro Posadas’

Medical centres and the medical systems within which they operate are unique and complex, and so embody their own institutional organisational culture. The authors’ institution of Hospital Nacional ‘Profesor Alejandro Posadas’ (HNAP) is a tertiary health-care institution located in the suburbs of Buenos Aires, Argentina. As a general hospital for acute conditions, it provides high-complexity care.

The paediatric palliative care team (PPCT) was created in the haematology and oncology unit in 1996. In 2006, its objectives were redefined to include children with non-malignant conditions. Establishing an independent PPCT in a general hospital involves educating other health professionals. PPCT interventions through education at the bedside, lectures, workshops, and guidelines have led to positive changes in the management of children with life-threatening and life-limiting conditions over the years (Kiman et al, 2011a).

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During 2012, there were 4026 births in HNAP, 508 (12.6%) of which were premature and 23 (0.57%) of which were babies under 1 kg. The NICU admitted 943 babies, of which 22.6% had a congenital malformation, trisomy, or hydrops foetalis. The most frequent congenital malformations included brain malformations, congenital heart diseases, and gastroschisis. Thirty five out of 53 (66%) newborns with severe malformations and 14 out of 53 (26.4%) premature babies died during their first week (Comisión de Mortalidad Sector Epidemiología Area Programática, 2013).

Palliative care for newborns is still a developing area in HNAP, and although the staff are able to identify clinical factors or lethal conditions leading to a transition to palliative care, usually these factors are not how the goals of care are established. More often parental agreement determines whether a palliative care transition takes place, and so curative technological efforts often continue regardless of neonatal physiological conditions. Few neonatologists have been trained in providing palliative care to comfort and manage dying infants and their families. Despite the PPCT's 17 years of existence in HNAP, what the team does is not widely known, is often misunderstood, and is underused.

This situation is, however, being patiently modified through collaboration between the neonatology department and the PPCT. Whereas previously the PPCT had only been asked to care for one or two newborns per year, in 2012 the team was requested to support 12 patients. Of these, five died in the NICU. Diagnoses were neurological sequelae of hypoxic–ischaemic encephalopathy, undifferentiated brain tumour, hydrocephaly, thanatophoric dwarfism, and multiple malformations. Two babies stayed in hospital (one with cerebral infarction and the other with neonatal leukaemia) and five were able to return home despite their conditions and continued to be cared for by the team. These babies were affected by holoprosencephaly, Steinert disease, neurological sequelae, multiple malformations, and pulmonary malformation.

The PPCT has begun to be integrated into care more early through consultation for babies with a poor prognosis, such as hypoplastic left heart ventricle, since the institution of the cardiovascular intensive care unit (CICU) in 2007, a new area for infants and children with congenital heart diseases in the paediatric department. Last year, 145 babies with congenital heart disease were admitted to the CICU for surgery, 17 (7%) of whom died. The CICU requested PPCT support for 29 babies, of whom 10 died. This data provides a strong case for the ongoing

development and implementation of neonatal palliative care.

### **Patient case study: decision-making for compromised newborns**

Futility has been a matter of conflict in the NICU, where there is a lot of uncertainty about short-term and long-term outcomes. Determining what measures are indicated for major malformations, birth asphyxia, and extreme prematurity is challenging for neonatologists. The autonomy of parents as decision-makers is also controversial (American Academy of Pediatrics Committee on Fetus and Newborn, 2007; Batton, 2009; Weiner et al, 2011). An example of clinical practice helps to illustrate what needs to be taken into account in decision-making around compromised newborns.

#### **Milena's story**

Milena (pseudonym) was born at term (41 weeks), but her mother presented with placental abruption. Milena required resuscitation in the delivery room and had an Apgar score of 6/7 at birth. She remained in the NICU with mechanical ventilation and inotropics. A diagnosis of total anomalous pulmonary venous return was made. On her seventh day of life she presented with extreme bradycardia and seizures. Referral to HNAP was requested for an urgent surgical intervention to correct her cyanotic heart disease. Physical examination on admission assessed generalised oedema, cyanosis, bilateral mydriasis (asymmetrical pupil hyperactivity in response to light) and flaccidity in all limbs. Doppler echocardiogram confirmed the diagnosis. Given the presenting neurological situation, a brain ultrasound was performed but was reported as normal. Corrective surgery was performed and was regarded as successful. Milena was referred to the PPCT owing to her neurological condition so that the team could provide emotional support to the family and discuss a possible life-support limitation.

After 3 weeks, Milena's clinical status had not changed: she remained in a deep coma, quadriplegic, with no spontaneous eye opening. Requested studies for better definition scanning using electroencephalogram showed diffuse encephalopathy, isolated bursts of sharp waves in the right occipitotemporal region, and unanswered auditory and somatosensory potentials. Cerebral computer tomography showed decreased intensity in basal ganglia without signs of oedema. Vertebral column magnetic resonance imaging (MRI) was normal, but cerebral MRI showed evidence of anoxic processes in both thalami, the cerebellar

peduncles, and the brainstem. Screening for congenital hypothyroidism was performed because of hypotonia, and levothyroxine was introduced. A genetic study was also undertaken. Progressive respiratory weaning was attempted, with several failed attempts at extubation. Tachycardia related to blood draws was assessed as the only cause of pain. At this point, considering the need for elective tracheostomy and gastrostomy on a patient in a deep coma, the question of futility arose. A clinical case discussion was held with the assistance of cardiologists, attending physicians, cardiovascular surgeons, neurologists, and the PPCT.

Two approaches were proposed: Milena could remain hospitalised as a patient with neurological sequelae, tracheostomy, and gastrostomy, or life-support limitation could be initiated owing to her severe neurological damage. Both options were discussed and it was agreed that the patient's neurological damage was very serious, without any communication with the environment, without changes in neurological status during hospitalisation after having overcome the problems that led to acute hypoxia and haemodynamic instability, and with very poor prognosis. In addition, the status of the family was considered: the family had another oxygen-dependent 4-year-old child with a life-limiting condition.

The opinion of the bioethics committee was requested and, with their consent, an interview was conducted with Milena's parents. It was explained that given the baby's clinical condition it was not advisable to undertake any further invasive procedures and it was suitable to provide comfort care and pain management. After this information had been communicated, both parents were involved in the decision-making. Aggressive treatments were limited (e.g. increased ventilator settings, inotropic drugs). A week later, Milena died peacefully in the arms of her father.

During the time in which Milena required mechanical ventilation, an infusion of fentanyl and midazolam was maintained, reaching maximum doses of 3 mcg/kg/hour and 0.3 mg/kg/hour, respectively. After a month of mechanical ventilation, enteral clonidine was added in order not to increase opioids. Muscle paralysis was reserved for episodes of respiratory decompensation with high ventilation parameters. During procedures such as sampling and endotracheal tube change, Milena received sedation–analgesia. On admission to the CICU, when presenting with abnormal movements (seizures), she first received phenytoin and continued with phenobarbital 5 mg/kg/day. Her pain response was then assessed with increased heart rate and the Neonatal Pain, Agitation and Sedation Hummel

scale. An occupational therapist was also involved at this stage.

### *The role of communication*

Health professionals face many ethical dilemmas when breaking bad news. Often, these are related to telling the truth and showing respect for the autonomy of the patient (and/or the parents in neonatal cases) without harming them (non-maleficence). It is common practice to temper bad news, resulting in a 'partial' truth that is sometimes, in the worst case scenarios, based on falsehoods and omissions. These circumstances set a course in the illness trajectory for unrealistic expectations among both patients and families; these may cause more pain and undermine confidence in relationships with health professionals. Informed decision-making needs to be achieved through an ongoing process of 'unveiling' and education of the patient and family, with the mutual exploration of perceptions, expectations, beliefs, and values and correcting of misperceptions (Rebagliato et al, 2000; McGraw and Perlman, 2008). Initiating an end-of-life protocol involves defining what is meant by irreversibility, explaining the prognosis, identifying goals of care at the end of life, developing an appropriate treatment plan, and documenting all processes in the medical records (McConnell et al, 2004; Kiman et al, 2011b).

The first dilemma with Milena was related to the emergency cardiac surgery being undertaken before any deeper neurological assessment was performed, after an ultrasound could not define Milena's neurological status. More scanning before surgery might have led to the surgery not taking place, with subsequent shortened survival time and less suffering for the patient, family, and medical team. Conflicts arose with the cardiovascular surgeons, who wanted to proceed with all available curative options. As a result, the information provided to the family was contradictory and, faced with a father in 'denial', the family's response was to favour an alliance with 'more optimistic' team members. The PPCT diagnosis made the health-care team suspect potential problems: the mother's fatigue in caring for her infant, which was confirmed by her absence in the weeks before the child's death, and the possibility of complex grief in the sibling caused by the lack of information and participation in the care of her sister. This was enhanced by the father's state of denial.


### **Conclusions**

Working in the NICU places one in a position to witness not only the birth of a baby with a

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life-limiting condition, but also the birth of the relationship between the baby and his/her parents in adverse circumstances, posing the threat of psychosocial risk. The parents of this newborn will have their self-esteem severely affected as they abruptly experience a very different reality to the one they imagined and to the cultural expectations of motherhood. The promised state of maximum happiness and fulfilment becomes instead a state of extreme stress, vulnerability, and concern. The NICU inevitably becomes the first ‘home’ for the newborn for whom death appears, paradoxically, at the beginning of life. In this context, the PPCT should accompany the patient and the family and, if necessary, provide counselling to the neonatal health team. Thus, either before or after delivery, PPCT interventions point toward enrolling the baby in a family history, to be accepted as a subject beyond its survival prognosis. This is the authors’ main objective. 

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