Australian College of Neonatal Nurses Inc.
Clinical Practice Guideline

Palliative care in the neonatal nursery

Guidelines for neonatal nurses in Australia

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Background

Neonatal palliative care involves the provision of care for both the infant and the family.[1] Care may be physical, psychological, social, emotional and spiritual in nature. Research among neonatal nurses in Australia has identified facilitators and barriers to the provision of neonatal palliative care relating to organisations, the availability of resources and to the skills and knowledge of neonatal nurses.[2,3] Variation between settings was observed with a recommendation for neonatal nurses to work towards establishing neonatal palliative care as a supported model.[3] The Australian College of Neonatal Nurses (ACNN) aims to provide a general guideline for palliative care in the neonatal nursery. These guidelines may be adapted with acknowledgement to meet local policy requirements and health department directives.

Aim

To provide information and guidance to nurses working in neonatal intensive care or special care nurseries, on the care of newborn infants with life-limiting conditions and a short life expectancy.

Scope

To affirm existing statements of the definition and general principles of palliative care and to provide principles of care for the newborn infant, the parents, and the nurse providing care.

Definitions: in this document, 'nurse' may refer to nurse or midwife; 'newborn infant' refers to the neonatal period of 28 days and beyond, before first discharge home; 'parents' may refer to other family members supporting that role.

The decision for palliative care

The reasons for offering palliative care are many and varied. They include infants born at the edges of viability; the presence of complex or multiple congenital anomalies incompatible with prolonged life where neonatal intensive care will not affect long-term outcome; infants not responding to intensive care intervention, who are deteriorating despite all appropriate efforts, or in combination with a life-threatening acute event.[1,4]

There is considerable literature on making the decision for palliative care.[5,6,7,8] This document is intended to apply from the point in time that this decision is made.

Contents

1. Definition and standards 3
2. The nurse providing palliative care 4
3. Palliative care of the newborn 7
4. Care of the parents 9
5. Summary of neonatal palliative care principles 11
6. References 12
7. Further resources 14

Definition and standards

Palliative care

The World Health Organisation defines the primary goal of palliative care as the provision of quality of life for those with life-limiting conditions and further identifies palliative care for children as a special field that includes care of the family (WHO, 1998). The WHO principles of palliative care for children that apply to the aim and scope of this document include a) the active total care of the infant's body, mind and spirit, b) support for the family, c) beginning palliative care when the decision has been made, and d) successful implementation even when resources are limited.

Standards of palliative care

Palliative Care Australia published *Standards for Providing Quality Palliative Care for all Australians* in 2005 (PAC, 2005). The standards as they apply to newborn infants and pertaining to this document are:

> "Care, decision-making and care planning are each based on a respect for the uniqueness of the patient … and family. The patient['s] needs, … their family's needs and wishes are acknowledged and guide decision-making and care planning."
>
> "Care is coordinated to minimize the burden on … [the] family."
>
> "The [family] is provided with information, support and guidance according to their needs and wishes."
>
> "The unique needs of dying [infants] are considered, their comfort maximized and their dignity preserved."
>
> "The service has an appropriate philosophy, values, culture, structure and environment for the provision of competent and compassionate palliative care."
>
> "Formal mechanisms are in place to ensure that the [family has] access to bereavement care, information and support services."
>
> "Access to palliative care is available for all [infants] based on clinical need and is independent of diagnosis, … cultural background or geography."
>
> "The service is committed to quality improvement and research in clinical management practices."
>
> "Staff … are appropriately qualified for the level of service offered and demonstrate ongoing participation in continuing professional development."
>
> "Staff … reflect on practice and initiate and maintain effective self-care strategies."
>
> *Standards for Providing Quality Palliative Care for all Australians*, p. 6-7.

Sources

WHO (1998). Definition of palliative care www.who.int/cancer/palliative/definition/en

Palliative Care Australia (2005). *Standards for Providing Quality Palliative Care for all Australians*. www.pallcare.org.au

The nurse providing palliative care

Goals of nursing management

The aim of palliative care nursing is the effective management of pain and discomfort for newborn infants who cannot benefit from intensive care and to provide culturally sensitive support for the family.

Palliative care focuses on both the infant and his or her family.[1] The model of care must be family-centred and inter disciplinary. The team must work together to achieve a consistent, culturally sensitive and empathetic approach to the management of the infant and family in their care.

While palliative care often necessitates the nurse progressing from a therapeutic approach to an end-of-life model of care, palliative care is not a passive process but rather one that requires specialised skills, professional maturity and sensitivity to effectively manage and meet the individual spiritual, cultural and physical needs of the infant and family.[9] The attitudes, knowledge and willingness of staff to provide palliative care are important[1] and nurses with these attributes, even beginning practitioners, are able to provide quality care.

Skills and education

Effective palliation of the dying infant and care of the family requires a high level of communication and interpersonal skills. The nurse would benefit from a combination of professional experience and life skills to bring to his or her practice in this aspect of nursing care but not all nurses involved in palliative care will have the same level of expertise. A major challenge to the provision of compassionate and evidence-based palliative care in the neonatal nursery is the lack of formal education in most graduate neonatal nursing programs.[1] It has been reported that less than two per cent of undergraduate nursing and medical curricula in the US address end of life models of care[10] but no published data was found for Australia. The Royal Australasian College of Physicians emphasises communication as an essential element of learning and that updating these skills is a core component of ongoing professional development.[8] As professional development is a responsibility for all health care professionals, ACNN supports this principle and recommends all graduate neonatal nursing programs and each nurse’s ongoing professional development address principles of effective communication and the tenets of palliative care for newborn infants and their families. There are an increasing number of resources and workshops available to health professionals (see www.palliativecare.org.au).

Communication

Collaboration and mutual respect between disciplines is the optimal model of communication. While leadership almost universally lies with the neonatologist, communication must be open and respectful. All members of the team should be listened to, their concerns and anxieties acknowledged, and misunderstandings addressed and alleviated. The observation and insight of others including social workers, nurses, doctors, allied health and pastoral carers may all offer a worthwhile perspective in complex or difficult situations. Importantly there is evidence nurses may be the most significant source of information for parents in the neonatal nursery[11] and it is therefore vital that nurses are proactive, are involved in the decision-making process and provide consistent and honest communication to parents.

Nurses can facilitate parental discussion about options for end-of-life care and facilitate further discussion about the possible participation of significant others such as siblings or grandparents.[1] Parents should be actively involved and empowered yet this principle needs to be balanced with parental ability to make decisions, their emotional state and their cultural and religious mores. The nurse needs to assist the parents to convey their wishes but he or she must also be cognisant of those subtle cues that suggest parental anger, confusion or the physical needs of parents such as hunger, pain or discomfort.

Parents can also question their decisions about end-of-life care and can feel a sense of guilt. Many parents who reach consensus with the neonatal team and each other about the withdrawal of intensive care can later express concern and uncertainty about previous discussions. The nurse must be perceptive and insightful to this potential dissonance and be proactive in reassuring and listening to their concerns. It may be appropriate to discuss this apprehension with the neonatologist or team leader, or equally parents may be seeking reassurance or permission to let go. The nurse can provide affirmation that palliation and provision of comfort is the best course for their infant.

Consensus

Agreement among team members is essential for cohesion in the care-giving process. A close collaborative team facilitates consistency in communication and seamless care of the infant and family. Teamwork should also reduce stress in individual team members and provide moral support for those clinicians providing direct care for the infant and family.[1]

It is also important to include nursing students and less experienced team members in discussions about end-of-life issues and the provision of palliative care.[1] This model of interdisciplinary education and mentorship will facilitate the development of effective communication skills and promote the principles of palliative care in beginning practitioners.

Self care and care of colleagues

Nurses with limited experience or educational preparation may be asked to care for the dying infant and their family. Nurses caring for these infants can experience moral distress if there is conflict between competing values and nurses are unable to put moral choices into action.[12] Competing agendas may include personal or cultural mores, religious beliefs and organisational protocols.[9,13] This can result in significant stress and a variety of supports should be available to assist and support the nurse who works in the neonatal nursery.[1]

Interdisciplinary team meetings during the palliative care process are needed to agree on the plan of care, evaluate previous decisions and facilitate ongoing discussions of the parental needs and grief response.[1] As each family is unique, the frequency and length of these meetings will vary. More frequent and longer meetings may be required for more difficult decision-making processes and for those families with additional psychosocial or cultural or religious complexities.

Nurses involved in end-of-life care will inevitably share in the family’s grief and loss which may lead to disenfranchised grief, the hidden grief often downplayed in the clinical setting.[14] In recognition of this possible outcome there needs to be opportunity for nurses to work through their feelings in a safe environment.

Case review

Formal case review meetings after all deaths and critical incidents will be helpful for the neonatal team.[1] These meetings provide protected time for reflection and discussion. When case review sessions are well facilitated they provide an opportunity for clinicians to articulate their ideas, further optimising care and communication processes around end-of-life issues.

Case review meetings also provide opportunities to identify those nurses who require additional education and/or emotional support.[9,15] In these forums nurses and others may express feelings of sorrow and helplessness or conversely over-critical responses that suggest emotional fatigue or loss of empathy. The emotions of sorrow and helplessness are normal responses to grief and methods to manage these can be explored within the formal and/or informal networks of the neonatal service. Mentorship and collegial support by more experienced and professionally mature nurses can be invaluable.

The emotions of irritability, over-critical appraisal and other negative reactions may reveal individuals who have increased anxiety and stress.[13] It is the professional obligation of senior colleagues and peers to identify and guide those individuals in need of additional support and counselling. Reasons for this distress can be many and varied. Some nurses may believe that withdrawal of intensive care is contrary to their personal values or beliefs.[9] All members of the team must feel comfortable in articulating their concerns or discussing their point of view. It could be argued that an individual’s capacity to deal with their own spiritual, emotional and personal values and ideas about death often hampers their potential to be proactive and sensitive to the needs of families or patients in crisis.

Documentation and development of evidence-based guidelines

The development of an interdisciplinary evidence-based practice guideline is essential in the provision of sensitive and appropriate end-of-life care. The decision to discontinue intensive therapeutic care, the reasons for the decision, agreed management plans and parental reactions, concerns and needs should all be documented. The protocols, documentation and process of transferring to palliative care will vary between institutions and states within Australia. It is important that each neonatal nursery develop guidelines incorporating the appropriate health department directives. They will guide and assist clinicians who do not have the formal ethical or clinical background to readily access evidence-based practice guidelines. This will facilitate a culture that supports clinicians and promotes a consistent model of care and family-centred ethos.[1]

The delivery of successful palliative care to the newborn infant requires coordination and continuity of care across all situations and settings for the infant and family[16] and the commitment of all participants. It aims to relieve suffering and improve the comfort of the infant, and provide support and dignity to the infant and his or her family.[1] Palliative care and symptomatic relief should always continue after life support is no longer used.[17]

The family

Discussing palliative care with parents is not easy and requires a non-judgemental and informative approach.[1] There are three considerations in determining the treatment decisions regarding palliative care: the certainty of the diagnosis, the certainty of the prognosis, and the meaning of the prognosis to the family.[18] Avoid the terms 'withdrawal of treatment' or 'withdrawal of care' and explain that care of the infant will continue although with a different purpose.[1] Use plain language and/or visual aids to explain the extent of problems and to clarify medical terms.

Encouraging families to engage with the dying infant assists in the grieving process.[19] Opportunities for parenting care may arise that provide comfort to their infant, such as oral care or bathing. The palliative care plan can be individualised by asking each family what they want to do with their infant in the time available and assisting them to achieve it.[1]

Environment

The best physical space with privacy and comfort should be chosen but location will be dependent on the resources at individual facilities and the wishes of the parents.[1] Locations other than the nursery bed should be considered and may include a quiet, non-clinical room off the neonatal nursery, a delivery room or postnatal room or even somewhere outside the hospital. Ideally, the location should provide for as supportive an environment as possible including privacy, low lighting and noise minimisation. There should be enough space to accommodate the presence of other family members.

Implementation

Ensure the medical records have documentation regarding discussions with parents about care options and orders to cease or not implement such interventions as mechanical ventilation, cardiopulmonary resuscitation, monitoring of vital signs or blood sampling.[1] Documentation requirements are an essential part of unit-based practice guidelines.

Nurses need to be sure that appropriate information has been shared with parents, to explain the plan of care and reassure the family that care is aimed at enhancing comfort.[1] Allow parents and family to process information and provide options including access to their infant for holding, cuddling, kangaroo care, and discontinuing interventions that cause discomfort or pain.

If the transition to palliative care requires the removal of technological supports, gradually remove supports in a sensitive way.[1] The nursing and the medical team will determine what is discontinued according to each situation, such as monitor alarms, mechanical ventilation, removal of invasive lines, monitors, and the endotracheal tube. It is advisable to leave intravenous access in place as medications are normally required to relieve pain and discomfort. Continue any or commence pain-relieving medications and review as needed. Medications should be given in sufficient doses to alleviate discomfort and pain.

Supplemental oxygen may be given to provide comfort however it may be more appropriate to administer morphine if a baby exhibits signs of shortness of breath, such as nasal flaring, air hunger, colour changes, or gasping.[1] Ensure suction is available to gently remove secretions. Occasionally check to see if there is no heartbeat, maintaining a sensitive approach. If there is no heartbeat a medical officer is required to confirm this although there is no need to hurry.

Intravenous or enteral feeding is not usually recommended but intra gastric tube feeds may be given in some circumstances.[20] Use of a pacifier when administering sucrose may provide additional comfort during removal of tapes or tubes. Oral care should be maintained to keep mouth and lips moist and oral sucrose may be used to promote comfort.[1]

Provide warm wraps for the baby when cuddled. Allow parents and family members to hold the baby for as long as they need to.[1] Discuss the choices of mementos with the parents first, suggesting alternatives if the parents are ambivalent or refuse. Mementos can be obtained by nurses, such as lock of hair, hand or footprints on a card, and photos of the family together, if this is culturally appropriate. Permission to keep mementos with medical records should be explored in case parents change their mind but this will be subject to local protocols.

For various reasons parents may not be present with the dying infant. The mother may be ill, the parents and family may be geographically distant or the parents may not feel able to cope with being there with their infant. On these occasions it is important that someone else is delegated to take the role of the parent, whether another family member, a pastoral support person or a nurse.[1] This should be documented in case the parents wish to know what happened at a later date, and can be reassured the infant was not alone.

Care after death

Care of the infant and parents continues after the baby has died.[1] The infant is washed and dressed and the parents may choose to do this. Sometimes the parents will provide the clothes and these should always be used. Arrangements for funerals and the procedure for transfer of the infant should be discussed with parents. Social workers can offer assistance with these matters.

Autopsy may have been recommended or requested by parents. In some circumstances the initial discussion may not take place until after the death. There should be time for informed discussion when consent is being obtained and the nurse can fill an active and supportive role in the information-sharing process. Local legislation and health department policies will apply for the procedure of autopsy however a useful resource is the Perinatal Society of Australia and New Zealand Perinatal Mortality Group Clinical Practice Guideline (see www.psanzpnmsig.org).

A referral to a lactation consultant or similar service should be provided to mothers.[15] Most mothers who deliver after 20 weeks gestation will produce milk after the birth. This can be both physically and emotionally painful. Comfort measures to prevent and treat breast engorgement include application of cold packs, analgesic agents such as ibuprofen, use of a supportive brassiere (even during sleep) and limited expression for comfort. Include information on lactation suppression in unit-based guidelines and provide the mother with a local contact number for advice should it be needed once she is at home.

Care of the parents

The unexpected outcome

During pregnancy parents start to think about the baby, and imagine what it will be like once the baby is born. A survey of media articles on preterm infants showed that the majority of them described premature birth as a positive event. Most articles did not mention long-term disabilities and health problems.[21] The influence of the media in suggesting all newborn problems can be fixed[1] and a false sense of technological security is not helpful.[14]

For some parents there may be a prediction of poor survival prospects for their baby from antenatal investigations but for others the situation can be sudden and unexpected.[1] To be confronted with the prospect of the imminent death of their infant, or at best a poor prognosis for quality of life, is a time of critical decision-making for parents that will affect the rest of their lives.[14] Factors that make the death of a newborn infant especially difficult include self-blame and a sense of failure, the lack of memories, the lack of anticipation, and the prospective nature of grief.

Making the decision

Communication from staff is a key factor for parents when they are advised on discontinuing therapeutic care for their infant. Parents need regular updating on their infant’s condition, constant information and to be included in the decision-making for their infant.[22,23,24]

There are a few factors that help parents accept the decision to move towards palliative care: visible deterioration of their infant, the possibility that their infant is experiencing pain, and clear news on the infant’s condition and prognosis.[25] Allowing the parents to hold their infant has an effect in moving the process of decision-making forward.[24]

The parent’s perspective

Introducing palliative care to parents should always include reassurance that the health team will continue to provide the best care for their infant.[1] Health care staff should discuss the parents’ understanding of the situation and any specific beliefs they wish to honour, and encourage parents to participate and spend as much time as possible with the infant. Parents seeing and holding their infant before or after death is an essential bereavement option and families that lack this opportunity may have later regrets.[14] Parents appreciate staff providing photographs and other memorabilia as requested. They also value information given to them, including the provision of literature to read on palliative care and their infant’s condition.[26]

Parents want to know what to expect in normal grieving.[23] They may experience the loss of their sense of personal competence and power, changes in self-image, emotional responses and physical sensations.[14] Grief lessens over time but memories may revive feelings of grief many years later.

The way health carers assist families in crisis may have a significant effect on how parents experience and remember their loss. As an outsider to the parents’ grief the nurse must refrain from judging and acknowledge individual grief experiences.[14] Even after several years, parents remember the loss of their infant with a surprising amount of detail. They remember the comments health staff made, and what upset them at the time.[23] The behaviour from staff that is most appreciated by parents is the offering of emotional support, attending to the physical needs of the infant and parents, and educating the parents. Emotional support included spending as much time as practical with the family, talking about the infant by name, and allowing the parents to show their grief. Being flexible about hospital policies for the family[1] and helping parents create material memories of their infant are part of attending to the needs of the family.[27]

Parental response to grief may depend more on the compassion from health care providers than on any other factors. Parents also identify with health care providers who show emotion and appreciate this as evidence that they care for them and their infants.[28] The most common criticism of health providers was lack of support or frank insensitivity.[23] Parents with a dying baby may find it very stressful to be around other infants and their families and this should be avoided if possible.[29]

Cultural and religious considerations

Cultural and religious differences can affect communication style, beliefs in being an individual and the role of the cultural group, views of death and illnesses and decision-making approaches. Religious preferences such as baptism or naming ceremonies and other belief-related needs of the family should to be explored. Pastoral support where available should be offered.

There is little research on cultural differences that affect the provision of palliative care.[30,31] However, culturally specific support needs should be anticipated and provided where possible including use of a translator when required for accurate communication.[1] It is not possible to be fully informed on all cultural diversities nor can it be assumed that the individual identifies with all aspects of their cultural background, therefore effective communication is very important.[14]

Continued care of the family

Following the death of the infant the parents will require ongoing support to replace the support established in the hospital, especially if they return to family and friends who are not supportive.[14] This may take the form of phone calls (especially from staff involved in their care), visits to the family at home or community support groups. There should be follow up appointments at outpatient clinics with obstetricians, neonatologists, geneticists or bereavement counsellors. Lack of bereavement support may increase the risk of adverse health outcomes. Some parents may not want contact or support from the hospital[1] however details of other forms of support should be offered.

Summary of neonatal palliative care principles

- The aim of palliative care nursing is the effective management of pain and discomfort for newborn infants who cannot benefit from intensive care and the provision of culturally sensitive support for the family, within a family-centred ethos.
- Introducing palliative care to parents should include reassurance that the health team will continue to provide the best care for their infant.
- Parents should be actively involved and empowered yet this principle needs to be balanced with parental ability to make decisions, their emotional state and their cultural and religious mores.
- Cultural and religious differences can affect communication style, beliefs in being an individual and the role of the cultural group, views of death and illnesses and decision-making approaches.
- Parental response to grief may depend more on the perceived compassion from health care providers than on any other factors.
- Effective palliation of the dying infant and care of the family requires a high level of communication and interpersonal skills. The nurse must also have a professional maturity and confidence that a combination of professional experience and life skills bring to his or her practice, or be supported by a nurse with these attributes.
- Interdisciplinary team meetings during the palliative care process are necessary to agree on the plan of care, evaluate previous decisions and facilitate ongoing discussions of the parental needs and grief response.
- Agreement among team members is essential for cohesion in the care-giving process. A close collaborative team facilitates consistency in communication and seamless care of the infant and family.
- Collaboration and mutual respect between disciplines is the optimal model of communication. All members of the team should be listened to and their concerns, anxieties and perhaps misunderstandings addressed and alleviated.
- The decision to discontinue intensive care, the reasons for the decision, agreed management plans and parental reactions, concerns and needs should all be documented.
- Formal case review meetings after all deaths and critical incidents will be helpful for the neonatal team.
- The development of an interdisciplinary evidence-based practice guideline, specific to the institution, is essential in the provision of sensitive and appropriate end-of-life care.

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Further Resources

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