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SPECIAL ARTICLE

Perinatal palliative care☆

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Abstract Perinatal Palliative Care is a model of care designed to prevent and treat the physical, spiritual, emotional, and social needs of fetuses and newborn infants with life-threatening or life-limiting conditions. The care extends to the infant's family. It is delivered by an interdisciplinary team to improve the quality of life from the time of diagnosis (possibly in utero) into death and bereavement (days, months or years later).

To guarantee the access of this vulnerable population to high quality palliative care, structured programs and protocols need to be further developed in tertiary hospitals that treat highly complex obstetric and neonatal pathologies. Basic training is required for all the professionals involved.

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Abbreviations: GA, gestational age; NCPQPC, national consensus project for quality palliative care; PPC, perinatal palliative care.

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PALABRAS CLAVE
Cuidados paliativos perinatales;
Enfermedad limitante de la vida;
Enfermedad amenazante de la vida;
Muerte neonatal

Cuidados paliativos perinatales

Resumen Los cuidados paliativos perinatales son una forma de atención clínica diseñada para anticipar, prevenir y tratar el sufrimiento físico, psicológico, social y espiritual de los fetos y recién nacidos con enfermedades limitantes o amenazantes de la vida, que se extiende a sus familias. Se trata de una atención interdisciplinaria y coordinada que busca ofrecer la mejor calidad de vida posible, desde el diagnóstico (muchas veces intraútero) hasta el fallecimiento y el duelo (días, meses o años después).

Los cuidados paliativos perinatales constituyen una prestación de salud básica dirigida a una población particularmente vulnerable. Para garantizar el acceso a una atención de calidad es esencial desarrollar programas estructurados y protocolos clínicos en todos los hospitales terciarios que atienden patología obstétrica y neonatal de alta complejidad. Se requiere también una formación básica de todos los profesionales implicados.

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Introduction

Pregnancy and birth are words associated with joy and life. However, every day, obstetric and neonatal care teams face the management of foetuses and neonates that will die in hours, months or years, without reaching adulthood. Although the care of terminally ill patients was initially focused on the adult population, in recent decades, awareness has grown that there are often children that face the end of life without receiving adequate care. This motivated the publication in 2014 by the Ministry of Health of a guideline titled ''Paediatric Palliative in the National Health System: Care Criteria'',[1] which set a framework from which to launch the widespread implementation of perinatal palliative care (PPC) in Spain.

Palliative care is a clinical speciality developed to anticipate, prevent and treat physical, psychological, social and spiritual suffering, with a similar approach in every age group, from the prenatal period to old age, and at the same time particularities depending on the stage of life. The aim of PPC is to achieve the best possible quality of life for any foetus or neonate with life-limiting or life-threatening disease and their families, from diagnosis (in many cases prenatal) through death and bereavement. It is a holistic and interdisciplinary form of care that can last days, months or years, often combined with specific disease treatment (Fig. 1).[2]

The objectives of the Sociedad Española de Neonatología (Spanish Society of Neonatology) in publishing these recommendations are: a) to detail the basic elements that the health care system must offer patients facing the end of life in the foetal and neonatal periods, and b) to guarantee access to high-quality care, as a basic health care right, for all foetuses and neonates with disabling or life-threatening disease and their families.

Characteristics of palliative care

The goal of PPC is not to help neonates die, but to help them live at the end of their lives, optimising their quality of life and that of their families.[3] For this reason, these services are offered in different settings in a coordinated manner, including obstetrics clinics, inpatient wards, delivery rooms, neonatal intensive care units, maternity wards, primary care and follow-up clinics.[4] Two groups of diseases, diagnosed prenatally or postnatally, require PPC: life-limiting diseases and life-threatening diseases (Table 1).

In order to standardise palliative care, the National Coalition for Hospice and Palliative Care, in the frame of the National Consensus Project for Quality Palliative Care (NCPQPC),[5] published guidelines that identified 8 domains which, when addressed simultaneously, help pursue excellence in care.

Structure and process

Perinatal palliative care is delivered by interdisciplinary teams including physicians (obstetricians, neonatologists, physicians specialised in palliative care), nurses, midwives, social workers, psychologists and other professionals depending on the disease at hand. Parents play a key role in decision-making and care planning. A physician is designated to coordinate care and documentation and ensure the continuity of care. This includes the setting where care will be delivered at the end of life, as long as the necessary resources are available[6]; while home care has a positive impact on quality of life, neonates usually die in neonatal units.[7] Established, structured care pathways and clinical practice protocols are essential elements of PPC.[8]

Physical aspects

To identify the numerous possible symptoms, health care professionals and families must continuously monitor the patient.[9] While some symptoms can be controlled (pain, dyspnoea...), there are others that the neonate and family need to adjust to (weakness, anorexia...). For each symptom, providers try to identify the aetiology and contemplate, in collaboration with the family, the advantages and disadvantages of performing diagnostic tests and offer

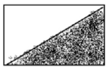	Progressive life-limiting diseases that result in death in a few months or years. As the disease progresses, the emphasis is gradually shifted from curative care to palliative care.
	Non-progressive life-limiting diseases that result in death in a few months or years that entail a higher vulnerability to health problems. Complex invasive treatments may be used to prolong life or improve quality of life simultaneously with palliative care, which may predominate in other stages of the disease
	Life-limiting diseases that cause death in utero or in the first hours or days post birth for which there is no curative treatment. Palliative care is offered from the time of diagnosis
	Life-threatening diseases. Palliative care is initiated once curative treatment has failed

Figure 1 Distribution of curative care (□) and palliative care (▨) based on different types of disease. Perinatal palliative care improves the quality of life of patients and families not only at the end of life, but in different stages of disease.

Table 1 Diseases diagnosed before or after birth requiring perinatal palliative care (PPC).

Groups of diseases requiring PPC	Subgroups	Most representative diseases	Integration of curative and palliative care
Life-limiting disease (no possibility of a cure)	Diseases leading to death in utero or the first hours or days post birth	GA ≤ 22—23 weeks	Palliative care is offered from diagnosis, which may be as early as the first trimester of gestation
		GA 23—24 weeks without life support Bilateral renal agenesis Anencephaly	
	Progressive disease that will cause death in a few months or years	Certain metabolic or neuromuscular diseases	Palliative care overlaps with curative treatment as disease progresses
	Non-progressive, irreversible diseases that cause severe disability and are associated with a higher risk of health complications	Trisomy 18 without major anomalies	Palliative care provided along with other treatments. As the risk of complications increases, palliative care gains importance in the treatment plan
		Cerebral palsy of various aetiologies	
Life-threatening diseases (there are curative treatments, but they may fail)		Extremely preterm birth	The patient receives life support. Risk of severe sequelae if the patient survives. Palliative care may be needed during acute disease and if curative treatment fails
		Certain congenital heart defects Severe congenital diaphragmatic hernia	

specific treatments—curative or palliative—that target the cause or the symptom.

Pain is one of the most frequent symptoms. There is evidence that supports the benefits of monitoring its severity and evolution through scales validated in neonates.[10] Depending on its severity, nonpharmacological or pharmacological interventions may be indicated, most frequently sucrose, paracetamol, morphine and fentanyl. Analgesia must be prescribed considering the half-life of the drugs to prevent resurgence of pain between doses. The preferred route of administration is the oral route and, when that is not an option, the endonasal route; the subcutaneous route is used exceptionally, and the intravenous route only considered if vascular access has already been established.

Psychological and psychiatric aspects

Professionals assess families from diagnosis and through gestation, the life of the infant and the bereavement process. The screening includes assessments of emotional and psychosocial distress in parents and siblings, and assessments of anxiety, depression and underlying mental health disorders. Psychology and psychiatry teams can provide care to all families or manage families specifically referred to them.[11]

Parents need support to participate in decision-making and to manage uncertainty and the complications of the disease and its treatment.[12] The family should also receive support for anticipatory grief and the changes in their everyday life associated with the burden of caring for the patient and, potentially, isolation and burnout.[13] After the death, support for bereavement should be offered for at least 13 months through phone calls, visits with mental health professionals or letters of condolence.[5]

Providers also need emotional support, which can be achieved by maintaining an open and respectful communication between professionals, through specific training, through counselling sessions following the death of the patient and regular consultations with mental health experts.[14]

Social aspects

Social workers assess the strengths, resilience and social support of each family in addition to their needs and weaknesses. The assessment includes an analysis of the family structure, the relationship with extended family, friendships and different community groups. The social worker also explores the economic resources, characteristics of the home and the ability to pay for additional expenses associated with the disease and the funeral. A plan is formulated with the family, identifying health care and social welfare resources that could be helpful.

Spiritual, religious and existential aspects

Palliative care also involves taking a spiritual history, identifying how parents seek and express the ultimate meaning and purpose of living, which is manifested through beliefs, values, traditions and rituals.[15] Their spirituality will influence their decision-making, experience of the disease, grief, and the process of death and bereavement.[16] In addition, a spiritual screen must be performed at key times to assess for existential distress, hopelessness or desperation that may warrant a full spiritual assessment by spiritual care providers, chaplains, etc.

Cultural aspects

The members of the interdisciplinary care team must be respectful of the culture, values and traditional practices of families, refraining from imposing their own.[17] They must also be aware of the potential challenges involved in these differences, especially when it comes to communication and shared decision-making. Established protocols and clinical practices must embrace cultural diversity and offer tools to manage it appropriately.

End-of-life care

Perinatal palliative care is not limited to end-of-life care, but is particularly important in the days preceding and following the death of the patient. The assessment and management of pain and other symptoms like dyspnoea, nausea, agitation or increased secretions (Table 2) is of particular importance, as are social aspects (preparing the funeral, burial or cremation) and psychological aspects (grief counselling and support in bereavement). This is also the time to bring up the potential benefits of performing an autopsy or post-mortem magnetic resonance examination and collecting samples of blood or other tissues. In collaboration with the transplant team, parents may be approached to consider donation of heart valves or corneas.

A significant proportion of deaths take place in the neonatal unit after the decision is made to withdraw or withhold treatment. As a last resort, in order to alleviate severe and irreversible symptoms refractory to other treatments, it may be necessary to deliver palliative sedation at the end of life (terminal sedation) through the controlled administration of drugs to induce a sustained decrease in the level of consciousness, superficial or possibly deep. Ideally, initiation of palliative care will result from a careful decision-making process by the team and the parents with consideration of the imminence of death, the severity and irreversibility of symptoms, the benefits of treatment, its risks and all possible alternatives.[18] This decision-making process must be documented in the health records. We do not recommend asking parents to sign a document, as it is not legally required and may exacerbate any feelings of guilt. The decision to withdraw or withhold treatment is made in collaboration by the family and the care team, which can alleviate feelings of guilt in the parents without limiting their autonomy.[19]

After death, the body should be handled respectfully and following the wishes of the family, and may include, among other possibilities, bathing, dressing in special garments, rituals, creating a special atmosphere through music, candles, etc.

Ethical and legal aspects

Parents and providers must make every decision in pursuit of the best interests of the minor, safeguarding the rights of the patient[20] and in adherence to current law and professional standards of care. The process of deliberation (considering the facts, moral dilemmas and possible courses of action) can guide the rational management of uncertainty in order to make prudent decisions.[21] Communication is an essential aspect of medical practice (Table 3).[22]

Table 2 Identification and management of symptoms in patients nearing the end of life.

Symptoms	Nonpharmacological interventions	Pharmacological interventions
Assess in every patient	Skin-to-skin contact, non-nutritive sucking, drops of breast milk or sucrose solution, voice, caresses, flexion, swaddling, rocking music, scents	
Respiratory distress (possible dyspnoea)[a]	Optimise neck and body position, treat hyperthermia, suction airway secretions, etc.	Opiates (first line). Benzodiazepines (adjuvant). In the case of hypoxaemia, oxygen therapy can be tried to see if it increases comfort
Increased airway secretions	Lateral decubitus or prone position to facilitate drainage Treat only if they cause discomfort. If secretions accumulate in the pharynx due to inefficient swallowing, consider mild oral suctioning	Atropine 1% eyedrops, sublingually. Glycopyrrolate
Constipation. Meteorism	Due to decreased motility, poor feeding, abdominal weakness, opiates, etc. Abdominal massage	Lactulose. Glycerine (suppositories or liquid formulation). Polyethylene glycol
Nausea. Vomiting	Due to gastrointestinal disease, activation of chemoreceptor trigger zone, opiates etc: consider reducing volume; positioning to reduce reflux	With caution, based on the aetiology, consider metoclopramide, domperidone, ondansetron, dexamethasone
Dysphagia. Anorexia. Hunger. Thirst	Differentiate symptoms due to electrolyte or blood glucose disturbances and weakness versus hypervolaemia, abdominal distension, nausea or vomiting. Offer drops of breast milk	Assess, with participation of the parents, whether tube feeding or parenteral nutrition should be initiated (or maintained) to improve comfort. Review the need for tube feeding at regular intervals
Dry skin. Itching. Cutaneous lesions. Oedema	Due to excessive pressure, rubbing, humidity, hypoperfusion, immobilization, medication, underlying disease etc.: changing position. Massage	Moisturizer or emollient creams. Vegetable oils. Other, depending on the aetiology
Dry mouth	Swab or gauze dipped in water or breast milk	Topical petroleum jelly on lips
Lagophthalmos		Artificial tears. Lubricant gel
Urine retention	Abdominal pressure. Adjust pharmacotherapy (in case of opiates)	In very select cases, consider urinary catheterization
Bone or muscle pain	Due to fracture or immobilization: adequate positioning. Massage. Physical therapy	
Perianal erythema	Frequent diaper changes. Exposure to air. Protective creams or ointments	Topical antifungals or antibacterials
Agitation	Consider cold, heat, noise, pain, hypoxaemia, anaemia, dehydration, urine retention, constipation, adverse drug events, psychological factors, etc	Consider benzodiazepines, neuroleptics, morphine, phenobarbital
Epileptic seizures	If underlying disease carries a risk of seizures, prepare the parents	Plan rescue treatment with parents (e.g. midazolam or diazepam)

[a] Gasping does not cause or reflect suffering, so it is not treated, but parents need to be educated about it.

Palliative care during gestation: particular aspects

At present, congenital diseases and malformations that may lead to the death of the patient during gestation, birth or in childhood are usually diagnosed antenatally. In spite of this, affected foetuses and pregnant women are rarely offered specialised palliative care.[23]

When a potentially life-limiting malformation or disease is diagnosed prenatally, the American College of Obstetricians and Gynecologists and the American Academy of Pediatrics recommend informing pregnant women of the different options available to them along with their risks and benefits, promoting their autonomy and freedom to choose.[24] Therefore, in addition to detailed documentation on different options for voluntary termination of pregnancy based on gestational age, pregnant women and their partners should be given information on PPC,[25] an emergent field focused on the complex management of foetal diseases and the overwhelming circumstances experienced by affected families, offering interdisciplinary care to those families that choose to seek it.[26,27] Follow-up care should also be

Table 3 Essential aspects of communication.

Setting	A room that offers privacy, seated, sufficient time Led by the most experienced physician with participation of the nurse and any other relevant professionals Offer parents the option of bringing other relatives or people they trust If necessary, schedule an interpreter, so that a family member does not have to fulfil this role
Characteristics	Be truthful and clear. Avoid technical lingo and long monologues. Be accurate, avoiding both euphemisms and excessive bluntness Speak tactfully, softly. Pause frequently, sometimes for a while, say what you have to convey slowly, giving time to parents to take in the information. Take into account the cultural background, beliefs and literacy of the parents. Acknowledge the emotions expressed by the parents Nonverbal communication contributes considerably to what is being conveyed: eyes meeting, the quality of a handshake, facial expressions, body gestures, posture, tone of voice Obtain information and verify comprehension by asking questions. Encourage parents to ask questions During gestation, call the foetus by their name, if parents already chose one. Use the correct sex in referring to the foetus Promote hope, highlighting the positive aspects that exist even in the most painful situations
Content	Communication is a process, not an act: offer information gradually, pick the main points and keep in mind the wishes of the parents In the initial conversation, due to shock, parents may have difficulty understanding and remembering some of the information In subsequent visits, explore what the family knows, expects and hopes for, and correct any misunderstandings. Add to the information gradually, considering what the parents want: What else would you like to know? What would you like to have happen? What are you most concerned about? Establish a care plan in cooperation with the parents, offering options, remaining attuned to their perspective, facilitating their participation in decision-making Identify and reinforce strengths Provide written information. Use graphs and diagrams if they can be helpful Families will search information on the internet: guide them in this search Facilitate access to parent, local and national associations

offered to parents that choose to terminate the pregnancy, including psychological support, if necessary.[28]

Advances in perinatal care have brought on the perception of the foetus as a patient that may receive specialised palliative care from the moment of diagnosis, addressing the 8 domains proposed by the NCPQPC.[5] In addition, during gestation, care should also focus on the life of the patient and the family, as opposed to merely waiting for the death to happen. The perceived bond with the child is profoundly affected by the diagnosis, and tends to be very intense once the initial shock wears out. The ultrasound examinations are a treasurable moment in the parent-child relationship, so attendance by other family members should be facilitated if desired, and the positive aspects of the foetus should be highlighted in the evaluation, as opposed to focusing solely on the disease. Tangible memories (pregnancy journal, images, video recordings of ultrasound examinations, recordings of the foetal heart beat) can be helpful during the pregnancy and in the bereavement process. A birth plan is developed with the parents and documented, and updated at regular intervals, including the time of monitoring to be used and the planned mode of delivery.

When birth is likely to coincide with the end of life, we recommend vaginal delivery unless otherwise indicated. The care plan includes directives regarding neonatal resuscitation, analgesia, sedation and the treatment of other symptoms. If the neonate is expected to survive for more than one hour, the care plan should include admission to the ward with the mother, the type and route of nutrition (including breastfeeding support), etc. If the prognosis is uncertain, different plans are established for each possible scenario.

At the time of birth, families should be allowed to plan how to welcome the child and the potential farewell. We recommend planning for the presence of relatives or friends, taking photographs or video, casting the hands and feet of the baby, bathing and clothing the baby, playing music and setting lights suiting the taste of the parents, etc. Parents should also receive support to perform, if they so wish, religious ceremonies or rituals according to their beliefs. Although it is a harrowing experience, most parents value having been able to accompany their child, and perceive this as a positive life experience that they can cherish later on.[29]

Conclusion

Perinatal palliative care is a basic health care service aimed at a particularly vulnerable population that is provided from diagnosis through bereavement. To guarantee access to high-quality PPC, structured programmes and protocols must be established in every tertiary care hospital managing complex diseases during pregnancy and in the neonatal period. Obstetricians, neonatologists, nurses, midwives and other professionals involved in the care of these patients must receive at least basic training on PPC. It is the responsibility of the care authorities, hospital administrators and department heads to allocate the specific resources required to allow implementation of PPC from gestation through bereavement and to promote research in this field.

Conflicts of interest

The authors have no conflicts of interest to declare.

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