

# Peaceful End of Life in an Unviable Newborn: A Case Report

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## Abstract

The limit of viability is a period of uncertainty regarding the prognosis and treatment, where palliative care (PC) is important to dignify death, although, in several countries, they are not implemented as in Colombia. The peculiarities of newborns make PC differ from care at other stages of life and which are rarely accepted by professionals who consider them overwhelming. The case of a newborn of 23 weeks of gestation is exposed where nursing care is revealed to the newborn and his family according to the theory of the peaceful end of life (PEL). The theory of the PEL is useful in the development of neonatal PC, which must be differentiated, improving well-being, and family support. Furthermore, health systems must recognize emotional risks for professionals.

**Keywords:** Extremely premature, fetal viability, infant, newborn, nursing care, palliative

## INTRODUCTION

In Colombia, 2499 newborns (NB) were born between 22 and 27 weeks of gestation during 2017 (extremely premature),<sup>[1]</sup> in a period that includes the limit of the viability, where the prognosis of life and clinical treatment are uncertain. Health professionals move between therapeutic incarnation, their obligation to save lives and the uncertainty of the benefits of palliative care (PC) in such small humans. This case reveals the nursing care framed in the theory of the peaceful end of life (PEL) and reflects on the care of ultra-premature NB.

## CASE REPORT

It is presented using the nursing situation methodology proposed by Boykin and Schoenhofer;<sup>[2]</sup> influenced by modern philosophies that recognize other forms of knowledge and board the human in an integral way.

The calm of the shift was interrupted by the arrival of a patient with 23 weeks of gestation, who needed an emergency cesarean section, by a rupture of membranes of a week of evolution with the signs of infection. Based on the calculated estimated weight, it was expected that the newborn would not be so immature, the health team agreed to be ready for revival.

When Jerome was born, the team agreed in that was better not to revive him for his immaturity. Jerome remained in deep apnea, hypotonic, and cyanotic, however, with the minimum

stimulus of taking anthropometric measurements, he began to sob and cry. He had his eyes fused and weighed 600 g. He was crying with such vitality that I asked again the conduct to follow; the pediatrician repeated that the baby was very immature, and it was not fair to subject him to an infamous quality of life (decision that was taken with the parents).

Once the medical evaluation was completed, the entire team left the site. I started talking to him, I performed all the protocol prophylaxis, I cleaned him, I got a nappy, I made a hat with a sterile compress, and I wrapped him with hot fields. I spoke with Jerome's father and facilitated his entry into the room, confirmed his religious beliefs with him and I applied sterile water to him making the sign of the cross, in a ritual that resembles the baptism of Catholics. The very shocked father left quickly. Again, Jerome and I alone, he looked cyanotic and with dyspnea, I wanted to run away and not hear his crying, but I stayed there to accompany him, to make his position changes, monitor his temperature and all those things proper to the attention of the NB. Three hours later, before finishing

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my shift, I handed him to my colleagues in the neonatal unit, saturating 69% and with great vitality in his expression. Finally, the newborn died in his mother's arms, 7 h after birth.

On leaving, I was able to release what I felt, I needed a few minutes of crying to understand that my profession is beautiful and demanding, requires strength and personal balance to face difficult decisions, but each one of the lived experiences broadens the vision of care and edifies a more integral human being.

The case allows to identify as protagonists the NB, his family and the nurse; transcending the positivist vision of the human divided into parts and the professional as an observer that does not change with the experience of caring. The focus is the PEL theory, as can be seen in Figure 1.<sup>[3,4]</sup>

## DISCUSSION

An element of PC is assistance for dignified death. Colombia decriminalizes assisted death in adults in 1997 and 20 years later materializes it; being the only country in Latin America to legislate on this aspect, but children are not included yet. Assisted death is not the only way to dignify death; however in such small and fragile bodies, the limit between comfort and assistance can be a very fine line. This circumstance creates anguish in health professionals, tension and distancing of PC; socially, the death of those who have just been born is not conceived. Therefore, neonatal and PC care is poorly boarded and defined in the care units.

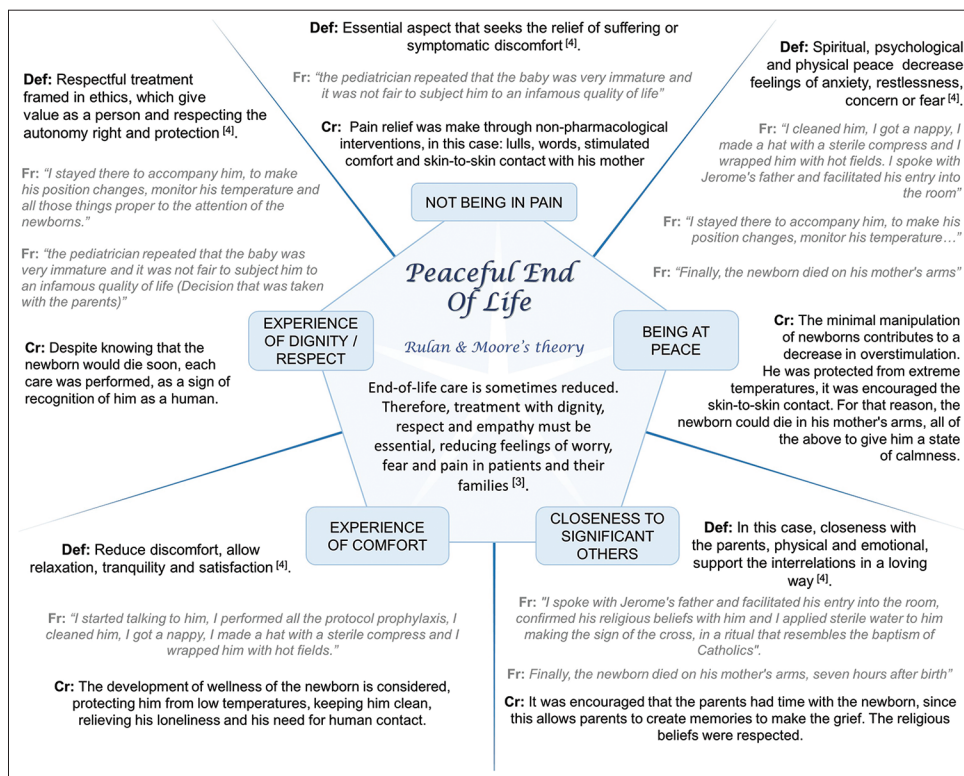
The peculiarities of NB do not allow PC activities to be inferred from care at other stages of life. In Figure 2<sup>[3,21]</sup> are the arguments that support the care activities reflected in the case.

The attention of the NB to the limit of viability requires a look focused on PC, to avoid suffering and dignify life and death.<sup>[22,23]</sup> The role of the nurse is: to support families for decision making that helps clear information; take care not only of physiological aspects but also participate in the defense of the patient and allow time, closeness and intimacy between the parents and the newborn;<sup>[23]</sup> as well as the other environmental aspects that favor tranquility and respond to the individual needs of each family.

The proximity to suffering and death leads professionals to emotional overload, intense sadness, and a sense of loss, so they feel fear of PC, relating to the lack of motivation.<sup>[22,24]</sup> This is seen as one of the most stressful activities for nurses and can be a cause of disinterest in the care, as they often experience great frustration. However, sensitive and differentiated care of families living this painful experience should be a priority.

Another circumstance that concerns health staff is the continuous balance between the beneficence and maleficence of treatments or the limitation of therapeutic efforts. As well as the constant reflection on the elements that constitute the well-being and quality of life of the NB.<sup>[19]</sup>

It should not be forgotten that the case on which it is reflected, exposes a highly sensitive moment where human treatment



**Figure 1:** Peaceful end of life theory in the case. The five concepts of the theory are defined; show a fragment of the case and the nursing care that was performed. Def: Definition, Fr: Case fragment, Cr: Care

CONCEPTS	PEL THEORY	RECOMMENDATIONS BASED ON EVIDENCE
NOT BEING IN PAIN	Pain is an unpleasant sensation caused by possible or materialized damage <sup>[9]</sup> . It is part of the PEL experience, where the absence of suffering is desired.	Pain contributes to the secretion of hormones such as catecholamines and cortisol, with effect on vital signs, catabolism and decreased functioning of the immune system of the NB. The processes of transmission and response to pain in the NB are altered by immaturity and at a lower gestational age, the difficulty to expressing pain is greater <sup>[8]</sup> . Monitoring and administering pain relief through pharmacological interventions or not is a priority <sup>[9]</sup> . Among the non-pharmacological interventions are: The administration of sucrose, breastfeeding (more effective when skin-to-skin contact is made), non-nutritive breastfeeding, kangaroo-mother care method, facilitated tucking, massage and music therapy <sup>[9,10]</sup> . The management of neonatal pain continues to be an unattended care <sup>[10]</sup> , among the aspects that limit clinical practice is the disproportionate application of tests to assess it <sup>[11,12]</sup> despite Ibero-American Consensus, professionals committed to the diagnosis and proper treatments of pain are scarce. In the case pain is not objectively assessed.
EXPERIENCE OF DIGNITY / RESPECT	Recognize the patient as a human being, taking into account his value as a person, respecting the principle of autonomy <sup>[9]</sup> .	Recognize the NB as a human, regardless of the law: "Greater than or equal to 22 weeks of gestation or 500 grams birth weight" <sup>[13]</sup> . In respect to dignity, the parents should receive information about the risks, benefits and prognosis, in understandable language. It is they who assume the autonomy of the NB and they participate in a decision shared with the professionals. These decisions must consider ethical principles, consequently children should not undergo painful interventions if they will not obtain benefits <sup>[14,15]</sup> . When active attention is stopped, the NB must be kept warm, comfortable, minimizing suffering and unnecessary stimuli and promoting NB contact with his parents <sup>[16]</sup> . Dignifying their implies attending to their needs, accompanying their and doing for it everything that is required.
EXPERIENCE OF COMFORT	It refers to the relief of discomfort, promoting tranquility <sup>[9]</sup> ; Rest and relaxation. Complication prevention is included here <sup>[9]</sup> .	There are adaptive responses that the NB assumes in extra uterine life. He must face the cold, but until week 28-30 of gestation he acquires the ability to increase the metabolic rate. This response is limited and even more so in preterm NB due to the low reserves of glucose, glycogen and lipids <sup>[17]</sup> . To favor thermoregulation, he must be dried with prewarmed fields to reduce conduction losses, remain wrapped to reduce convection and evaporation losses; and employ a natural heat source such as skin-to-skin or artificial contact such as incubators <sup>[17]</sup> . Facilitated tucking is important, because the fetus is accustomed to the uterine space that presses him to adopt the strapping posture. This therapy offers he peace of mind <sup>[18]</sup> . Other cares such as postural changes are important, to prevent skin lesions and promote circulation <sup>[18]</sup> . The maintenance of hydration and caloric intake of the NB, requires the administration of intravenous fluids; its condition of ultra prematurity hinders the insertion of venous accesses <sup>[19]</sup> and the umbilical catheter is frequently used.
BEING AT PEACE	Within the state of tranquility, calm and satisfaction, it is required to minimize states of anxiety, agitation or worry <sup>[9]</sup> .	Care such as reducing noise, light, manipulation, painful stimuli and stress contribute to the tranquility of the NB <sup>[18]</sup> . Promote his comfort, control pain, promote thermoregulation, offer oxygen and of course, you should not miss contact with parents, ensuring time and privacy <sup>[20]</sup> . NB at the limit of viability experience difficulty breathing, because their lungs are not ready to function. The choking sensation can be lessened with the use of mild sedation. This therapy is often performed with short-acting sedatives such as midazolam, morphine, dexmedetomidine, among others. Professionals avoid the use of sedation because of the known negative effects on future neurodevelopment <sup>[21]</sup> . Ultra premature NB who will not survive can benefit from their administration.
CLOSENESS TO SIGNIFICANT OTHERS	It has to do with the feeling of being related to other people who care, including physical and emotional closeness <sup>[9]</sup> .	The family is not prepared to see die who are just born, their fragility and innocence deepen the impotence. Skin-to-skin contact between the mother, father and the NB is a therapy with kind effects on emotions <sup>[9]</sup> . It offers peace of mind and allows parents to build memories that help the subsequent elaboration of the grief. Including parents in decision making <sup>[14]</sup> , ensuring time for parents and children to meet <sup>[20]</sup> and in general giving a sensitive, comprehensive attention that responds to the particular needs of each family, are actions to that professionals downplay and should be a priority for the comprehensive care of the death of those who have just been born.

Figure 2: Scientific evidence of the care oriented by peaceful end of life theory

must be gentle, considerate, and honest.<sup>[25]</sup> These require that the health staff involved receive frequent training, and this topic is involved in the agendas of the neonatal care units.

### CONCLUSION

- Neonatal PC is important to promote a dignified death in those who have just been born
- The care must be multifactorial, sensitive, and differentiated, improving the well-being of the NB, and promoting family support
- Professionals working in neonatal units must commit to the attention of NB to the limit of viability and health systems must recognize the risks to the emotional health of professionals and the needs of special training
- The PEL theory is useful in generating the comprehensive neonatal or perinatal PC plan and favors evidence-based practice.

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