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Towards a new Protocol for Advance Care Planning in severe prematurity. A personalist perspective

Hacia un nuevo Protocolo para la Planificación Anticipada de Cuidados en casos de prematuridad grave. Una perspectiva personalista

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Abstract

The most serious and ethically complex decisions concern extremely preterm infants (< 27 weeks of gestation), where both active life-support and palliative care may be considered within the framework of Advance Care Planning (ACP). This planning arises when survival is uncertain or future quality of life raises serious concern. In this process, parents, physicians, and healthcare teams must decide for a patient unable to express their will, while Clinical Ethics Committees may provide guidance. This article examines these dilemmas through a Personalist bioethical approach, introducing the Personalist Advance Care Planning Protocol for "extremely premature infant"/EPI (PACP-PEPI). This seven-step dynamic protocol advocates dialogue, proportionality, prudence and continuous review as ethical foundations for compassionate and coherent neonatal care that safeguards dignity and strengthens parental trust.

Keywords: extreme prematurity, ontological personalism, advance care planning, ethics committee.

1. Introduction

Prevention of preterm birth is a national emergency and priority in several countries, such as the United Kingdom (1), France (2), and Italy (3). Guidelines are provided for developing prevention strategies, including effective communication between healthcare professionals and parents (mother and her partner). The aim is to ensure better active care (sometimes, it is referred to proactive care) or palliative care, for the unborn baby. Usually, active care refers to all obstetric and neonatal interventions that aim to provide a better environment for sustaining the baby's life (4,5). On the other hand, palliative care consists of all medical procedures aimed at ensuring greater comfort if the baby is facing the end of life (6,7). Between these two types of care lies a "gray zone". The "gray zone" is "a set of clinical situations in which resuscitation and intensive care will be

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provided to newborn infants if parents so wish, or will be withheld/ withdrawn (and palliative care provided) if parents choose" (8). However, the decision-making process involves several key players [2] and the decision depends on the bioethical assessment in extreme prematurity [3]. In this complex climate, it is important to analyze the place and role of Advanced Care Planning [4].

2. Decision-Making Process

Severely preterm infants face a high risk of mortality and, if survival is achieved, long-term disabilities. The clinical decision lies between initiating or continuing intensive treatments or opting for palliative care. The ethical difficulty arises because the patient cannot express their wishes, leaving parents, the physicians [A] and the Ethical Committee [B] to act in the extremely premature infant's (EPI) best interest. This decision-making process becomes more complex when confronted with multicultural context and religious belief [C].

A. The role of parents and physicians

Parents are the natural decision-makers for the child, yet their choices must be guided by the principle of the EPI's best interest (9), not only by subjective fears or hopes. Physicians have the duty of truth-telling (10)that is beneficence, nonmaleficence, autonomy, and justice, are defined and explained. Informed consent, truth-telling, and confidentiality spring from the principle of autonomy, and each of them is discussed. In patient care situations, not infrequently, there are conflicts between ethical principles (especially between beneficence and autonomy and of providing realistic prognostic information, balancing beneficence and non-maleficence. Consequently, each act to manage labor, birth, and neonatal care period should reflect and respect the "wishes and values of the mother and her partner" (1, p. F233). However, parents' preferences must

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not conflict with the recommendations of healthcare professionals. Parental responsibility offers a wide margin of discretion that can be modified according to the circumstances that may arise; nevertheless, this discretion is not absolute (11, p. 156).

B. The role of ethics committees

Given the complexity of these decisions, and in cases where parental requests clash with medical judgment, ethics committees can serve as ethical mediators, helping families and medical teams to identify morally justifiable courses of action. Usually, these committees do not impose solutions but support conscience formation and relational responsibility. Around 26% of cases with ethical decisions in clinical practice in NICUs are presented to ethics committees (12, p. 985).

In this context, it is useful to involve the Ethics Committee for Clinical Practice of the healthcare facility, especially if family members request therapeutic measures that the medical team does not consider appropriate (13, p. 35)medico e teologo, sacerdote e professore di Bioetica presso la Pontificia Università della Santa Croce (Roma. The procedures for consulting the Ethics Committee may not meet the desired response times. Many ethical decisions are made urgently, and there is not enough time to follow the rules for convening a hospital committee. For this reason, it is possible to set up a 'task force' composed of three members of the Committee and two specialists recognized as having specific expertise in the area of intervention. This micro-group must produce an ethical opinion within 48 hours of the request. The intervention of a single bioethicist is considered inappropriate because it may not respect ethical pluralism, an essential element of bioethics (14).

C. The role of the mediator

In multicultural, religious belief or even immigration context, the contribution of mediators is particularly important.

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Religious freedom is protected and valued in the constitutions of many nations, such as France and Italy. Conflicts due to religious beliefs may arise either from the physician's position (15) or from that of the child's family (16). However, and in any case, all therapeutic interventions must be proven effective, capable of preventing, treating, and improving serious illnesses with a view to preventing future harm to the child. This is why the mediator's role is to structure counseling that facilitates dialogue between healthcare professionals and parents in cases of conflict based on religious beliefs.

In addition, studies have shown that "language barriers play a critically important role for the development of immigrant children born" very preterm birth (17). This is because parents feel alone and lack understanding when it comes to their premature babies' healthcare needs. But also, the language barrier leads to a high risk of inadequate prenatal care among migrant women (18).

The existence of barriers that make relations between health services and immigrant patients difficult is undeniable and overcoming them requires not only figures such as mediators, but also adequate knowledge and awareness of the dynamics that govern the negotiation of meaning between healthcare personnel and foreign patients. In fact, it is noted that within the relationship between doctor and non-EU migrant patient, there is considerable difficulty in understanding. It is not only for linguistic or purely ethnological reasons, but also because of the expectations of migrants who experience an ambiguous situation of detachment from a past that is never definitively abandoned and a desire for integration into the new world that they are unable to achieve fully.

Among the risk factors for health, we should mention the slowness of integration processes, psychological distress, lack of work and income, poor housing conditions, lack of family support, different climates and eating habits, and discrimination in access to health services, often linked to bureaucratic and linguistic-cultural barriers. Finally, regarding the concept of healing, while in Western culture the doctor is central to the healing process, in many other cultures this role is taken by a traditional religious healer (19, p. 34).

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3. Bioethical assessment in extreme prematurity

Evaluating the decision-making process depends on three main factors: the nature of the EPI's best interests [A], the risk assessment [B] and which bioethical model is adopted [C].

A. The EPI's best interests

EPI's best interest is the first ethical principle to consider. The *United Nations Convention on the Rights of the Child* (CRC) (20) insists on the best interests of the child in many articles (art.):

- Art. 3: best interests of the child in public or private social welfare institutions;
- Art. 9: a child must not be separated from his/her parents;
- Art. 18: role and responsibility of the parents;
- Art. 20: right to a family;
- Art. 21: adoption;
- Art. 37: no child shall be subjected to torture or other cruel, inhuman or degrading treatment or punishment;
- Art. 40: accused child and penal law.

The *European Convention on Human Rights* (ECHR) (21) is also relevant to understand what rights could be relevant with the best interests of the child:

- Art. 2: the right to life and the positive duty to protect it;
- Art. 3: the prohibition of inhuman and degrading treatment;
- Art. 5: the right to liberty and security of the person;
- Art. 8: the right to respect for private and family life;
- Art. 9: the right to freedom of thought, conscience and religion;
- Art. 14: the prohibition of discrimination in respect of enjoyment of the other rights.

However, despite these rights and duties, it is difficult to have a unique definition of EPI's best interests principle due to clinical evolution

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and subjective evaluation (22). For some (23), the EPI's best interests is a sum of various interests, such as medical care (related to pain and suffering) and other potential interest (quality of life). For others, best interests are not only medical or clinical interests but also social, emotional, political, cultural, religious beliefs and moral (24, p. s11). Concretely, withdrawing (removal of a therapy that has been started), withholding (not to make further therapeutic interventions) or limiting treatment could be for the best interests of the EPI (24). In some cases, the EPI's best interest could be in conflict with parent's interest, as for example when parents ask for the baby not be resuscitated while their EPI is in good condition to survive (22). In addition, even if parents know their children better than others do (mood, traits, character, preferences, fear, etc.), it does not mean that they know what is best for those children. The reasons can be various: selfless motivation and subjective-emotional decision that creates a gap between the reality and the normative judgment, such as parent's hesitation or refusal to vaccinate their children, and fear of long-term side effects versus the expected benefits against disease (25). But also, but also there is the possibility of some unreasonable decision that may harm the child (obliging a child to follow a diet) (9).

The first step to determine the best interests of the EPI, is to proceed to risk assessment.

B. The risk assessment

For babies born before the 22nd week of gestation, it is usually advised to not attempt to resuscitate (1). Scientific evidence shows that the survival rate of newborns with a gestational age of less than 22 weeks is practically zero. Although this case could be defined as probabilistic futility, it is more likely that it reflects the physiological inability of immature lungs to perform their essential function, resulting in a case of physiological futility (11, p. 63). The development of a condition of physiological or probabilistic futility may be a solid justification for deciding to suspend or discontinue supportive

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therapy. This decision is delegated to physicians and must be communicated with extreme sensitivity, given that parents are often unable to accept the inevitable death of a child (11, p. 64).

As for the babies born after 22nd week of gestation, risk assessment is divided into three groups (1,26): extremely high risk [a], high risk [b] and moderate risk [c].

a. *Extremely high risk*

For EPI at extremely high risk, palliative care would be the usual management. The ETHICUS study of C.L. Sprung *et al.* (27)ethical dilemmas are occurring because of forgoing life-sustaining therapies in intensive care and are dealt with in diverse ways between different\ncountries and cultures.ObjectivesTo determine the frequency and types of actual end-of-life practices\nin European intensive care units (ICUs considers four possibilities in critical conditions: a) continuing with full support, b) not undertaking any therapeutic procedures, c) discontinuing treatment, and finally, d) actively causing the patient's death.

In French, the expression "limitation et arrêt des traitements" (limitation and termination of treatments) is often used in the context of end-of-life cases, but is also applied in cases of extreme prematurity (28). It stems from the principle of refusing unreasonable obstinacy (formerly known as therapeutic obstinacy) as defined by the Leonetti Law (Art. L. 1110-5-1 of the French Public Health Code). It consists of not implementing or intensifying active treatments. In Italian, the expression "desistenza terapeutica" (29) has become established, first in intensive care and then in other areas of medicine. It refers to an approach to sick people at the end of their lives that consists of suspending or not activating therapies that are now considered ineffective or disproportionate and simultaneously activating more appropriate and meaningful forms of support. In Spanish, the term "limitación del esfuerzo terapéutico" has prevailed, which sometimes also includes the diagnostic part. In the

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Anglo-Saxon world, generic terms such as "forgoing" or, more frequently, "withholding" and 'withdrawing' are used to indicate "not starting" and "stopping" treatment, respectively. This often leads to the more generic term "end-of-life decisions" which includes both therapeutic limitation and palliative measures, including those voluntarily aimed at hastening the patient's death (13, pp. 38-39)

b. *High risk*

For EPI at high risk, it is recommended to provide active management (survival) or palliative care on the demand of the parents. The aim is to optimize the baby's condition at birth. For these babies, with a >50% risk of death or of surviving with severe impairment despite treatment, parents should be counselled carefully and parental wishes should inform a joint decision to provide either active or palliative treatment (1).

c. *Moderate risk*

For fetuses/babies at moderate risk, active management should be planned. These babies have a <50% risk of death or of survival with severe impairment; active management would be in the best interests of the baby through evaluation and collaboration a senior neonatal clinician (1,26).

While risk assessment is the starting point to seek the EPI's best interests, the situations are more complex because they raise various ethical questions, especially when it comes to the "gray zone". It corresponds to the period between the 23rd and 27th week of gestation, depending on the policies of each country: in France it is between the 22rd and the 23rd week of gestation (30); in Italy, the limit is set at 22 weeks (31, p. 82); according to Dutch guidelines (32), it is between the 24th and the 26th. In such period of prognostic uncertainty, which management approach is in the EPI's best interests? Is it to proceed with active management or palliative care? Hence, the importance

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of accompanying this assessment with an ethical evaluation, which differs depending on the model adopted.

C. Bioethical models

Multiculturalism and pluralism of thought necessarily imply a variety of approaches to bioethics. We have chosen to discuss two main ones: Principlism bioethics [a], since it is the most widespread model and, Personalist bioethics [b], since it is the model we advocate.

a. *Principlism bioethics*

Principlism bioethics is an established approach founded by Tom L. Beauchamp and James F. Childress. In their book *Principles of Biomedical Ethics*, the authors advocate for four principles that have virtually become standard practice in healthcare sector around the world: autonomy, beneficence, non-maleficence, and justice. To help realizing the EPI's best interests, applying these principles in the context of extreme prematurity leads to the following scenario.

First, since the baby does not possess any conscious faculties enabling him to have the capacity and maturity to make decisions, autonomy in extreme prematurity is mediated through surrogates (parents and professionals), as explained in section I.

Secondly, beneficence and non-maleficence compel clinicians to evaluate both probabilistic futility —when physiological immaturity makes survival virtually impossible— and proportionality, ensuring interventions offer true benefits, minimize suffering and avoiding potential harms (33). Beneficence, as an act of doing good, includes mercy, kindness, charity (34), and generosity (35) towards patients; but also, it implies protecting the patient especially when it comes to babies (36) and promoting his/her well-being (33). For its part, the principle of non-maleficence implies not causing harm. Although it seems complementary to the principle of beneficence, there are situations where the two principles are contradictory. Take the example

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of a newborn who needs to be fed through a tube. While feeding is beneficial, inserting the tube causes harm. What is right and what is wrong in this case? It is also the same ethical case when it comes to withdrawing or withholding treatments, that may cause harm, even death. The question arises: is the process consistent with beneficence and non-maleficence? What is the EPI's best interests?

Thirdly, as for the principle of justice, art. 10 of the Universal Declaration on Bioethics and Human Rights (37) stipulates: "The fundamental equality of all human beings in dignity and rights is to be respected so that they are treated justly and equitably" (37). According to this article and the articles of the CRC and the ECHR, the principle of justice operates on two levels. On the one hand, all children must be treated justly and equitably, with the same consideration regardless of their ethnicity or religion, but also regardless of their social situation. However, the reality shows some structural discrimination issues (38,39), a form of institutional discrimination, such as lower-quality-care (40,41) because of racial and ethnic disparities. On the other hand, the principle of justice is related to health equity regarding the costs of the healthcare. Indeed, estimations reveal that the neonatal intensive care has the highest expenditures than that for the babies born at 40 weeks or full-term babies (42–45), which raise the question of waste and constraints on resources. Thus, the ethical relevance of cost-effectiveness is crucial in the decision. For example, studies have shown that resuscitation of neonates is not cost-effective due to extremely high long-term costs (46,47). In addition, and at the same time, there is the question of cost-effectiveness and cost/quality-adjusted life-year (QALY). Thus, is it sufficient to save the newborn infant knowing that the adverse outcomes could make his life miserable (48) and generate greater costs (49)? Does this fall within the category of his best interests?

Although these principles establish ethical rules for crucial issues in extreme prematurity, it seems that they are insufficient to serve the best interests of the child for two main reasons. On the one hand, in the event of a contradiction between these principles, how

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can the conflict be resolved? On the other hand, these principles have a utilitarian bias that may override the best interests of the child because it may be too expensive to treat her/him (50,51). This is why it is necessary to have a solid ethical foundation in order to avoid these two crucial issues.

b. *Personalist bioethics*

Among the numerous bioethical models, Personalist bioethics affirms that every human life has intrinsic value regardless of health condition or prognosis. Personalism places the human person at the core of ethical reflection, asserting that each individual possesses inalienable worth regardless of developmental stage or health status. Thus, dignity is not conferred by capacities but by the very fact of being a "human being". This also applies to the unborn child who has already been conceived (52, pp. 60-63, 123-125, 461-470).

This contrasts with utilitarian or strictly consequentialist approaches, which may weigh the worth of life based primarily on projected quality of life. In a multicultural society, this principle serves as an anchor against cultural relativism, ensuring that human dignity is always the starting point of ethical deliberation.

An important ethical issue concerns the value of neonatal life and, consequently, the strength of the right of access to care for an extremely premature newborn. The subjective dimensions of quality of life can only be hypothetical due to the patient's natural inability to formulate them. When clinical decisions are made, it is not possible to invoke the principle of autonomy. Those who must decide must refer to the principle of promoting life.

According to the personalist view, every newborn has the same dignity and the same right to care. This right does not mean the right of everyone to the same care. There is no obligation to intervene beyond the limits of reasonableness, which both parents and healthcare personnel must necessarily bear in mind. The starting point is the fundamental right to existence and proportionate care. Intensive

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care for newborns with a chance of survival and compassionate care for the most seriously ill with little chance of survival have the same meaning and dignity (53, pp. 123-124).

Intensive resuscitation with EPI can cause permanent damage and even death to the patient. In fact, the most common causes of death are severe respiratory illness, intraventricular hemorrhage, and sepsis (including necrotizing enterocolitis) (54). In such clinical situation, two personalist principles can shed light on the situation for ethically acceptable biomedical actions.

i. *The "double effect" principle*

In critical situations, good medical action, sometimes even necessary, has a predictable negative consequence. This is where principle of "double effect" must be applied (52, pp. 177-178). Where there are reasonable grounds for resuscitating a newborn baby through complex therapeutic intervention, for which there are no other remedies free from negative effects, it is permissible to perform —or omit— an action when the choice also involves a negative effect, provided that the following conditions are met:

- The act itself, regardless of the harm caused, is good or at least indifferent;
- The agent's intention is inspired by a positive end;
- The good effect is not achieved through the bad effect;
- There is a proportionately serious reason for allowing the bad effect to occur.

ii. *The principle of totality and/or the therapeutic principle*

Secondly, it is especially in premature newborns where we can observe the "unitary whole" of human corporeality, which consists of distinct parts that are organically and hierarchically unified by a unique and personal existence. The little patient has no capacity to act and depends on the decisions of others, but by working to save

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his life, his physical integrity must be protected. In the particular situation of extremely premature newborns, according to the totality's principle, we must necessarily add, in addition to subjective well-being, psychological and social well-being, observing the overall results that also involve the parents. An example could be the case of necrotizing enterocolitis (NEC) that is the most common gastrointestinal emergency in newborns (55). Necrotizing enterocolitis is a life-threatening disease predominantly affecting premature and very low birth weight infants resulting in inflammation and necrosis of the small bowel and colon and potentially leading to sepsis, peritonitis, perforation, and death; its etiology involves bacterial colonization, enteral formula feeding, and hypoxic-ischemic injury (56). Emergency bowel resection is currently practiced, but consequences of intestinal resection are very serious. The small intestine leading to short bowel syndrome (SBS) deprives an organism of many immunocompetent cells concentrated in gut-associated lymphoid tissue, the largest immune organ in humans (57), but the most serious outcome of the surgery is dependence on TPN (Total Parenteral Nutrition) for many years or for life (58), with a subsequent compromise in quality of life. However, the operation is necessary to save the newborn's life.

In order to be ethically acceptable, these interventions based on the therapeutic principle must meet the following conditions:

- That it involves surgery on the diseased part or the direct cause of the disease, in order to save the healthy organism;
- That there are no other ways or means to cure the disease;
- That there is a good and proportionate chance of success;
- That there is consent from the patient or the person with legal rights (in this case, the parents).

In summary, Personalist bioethics is characterized by a holistic approach based on the ontological dignity of every human being. Through the principles it proposes, it allows for the care of the whole individual (physical, mental, and spiritual) while ensuring their

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well-being. Thus, this model respects the proportionality of care avoiding excessive medical treatment.

4. Advance Care Planning

An important principle in palliative care is to develop and adapt Advance Care Planning (ACP) [A] that recognizes the uncertainty of outcomes and are able to adapt flexibly to changing circumstances (59). The personalist protocol [B] may be the best suited to ensuring respect for the EPI's best interests.

A. Adaptation of Advance Care Planning

Advance Care Planning is a negotiated, documented roadmap co-authored by clinicians, parents, and, when appropriate, religious support, outlining goals, thresholds for intervention, and comfort measures. It aims to provide comfort-focused care at birth for an EPI and helps to make the best decision in some critical situations. It may be revised after birth because the infant's condition is significantly better than expected and/or because the parents change their minds (1). The first case may occur because of the natural variability of the infant's condition at birth or because there was an error in calculating the gestation. The second case may occur because of the parents' reaction to seeing their newborn or because the newborn's condition is different from what they expected. Even parents who have made a clear decision not to use life-prolonging treatments may experience doubts when the baby is born (7).

It is therefore essential to schedule periodic reviews of the care program using "dynamic planning" (60) adapted to this specific clinical context. The dynamic nature of planning must be consistent over time; it can be set on specific dates or according to clinical developments, recorded in the patient's medical file. It should help to

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make logical sense, not grounded on emotional choices, but on Evidence-Based-Medicine (61,62).

In addition, it will be necessary to apply the principle of "therapeutic caution" while respecting the uniqueness of the patient (13, pp. 141-143)medico e teologo, sacerdote e professore di Bioetica presso la Pontificia Università della Santa Croce (Roma. For this principle, we can refer to Aristotle and his *phrónesis* (63), often translated as practical wisdom or prudence, a practical intellectual virtue that guides human action toward good rather than evil. This is not abstract theoretical knowledge, but an ability to deliberate and make good choices in concrete situations, based on correct reasoning and detailed knowledge.

Hence, the following protocol of ACP could serve as a basis for reflection, enabling careful discernment for the EPI's best interests. It recognizes changing prognoses and parental values, mandating periodic review before and after birth to respond prudently to clinical evolution and shifts in family wishes.

B. Towards a Personalist Advance Care Planning

Based on the above analysis, we propose [a] a Personalist Advance Care Planning Protocol for EPI (PACP-PEPI) based on two key innovations [b].

a. *The Personalist Advance Care Planning Protocol for EPI (PACP-PEPI)*

Our suggestion of PACP-PEPI is justified by the fact that it is well-founded on the principle of ontological dignity. Every human being, regardless of gestational age, health condition, or prognosis, possesses intrinsic dignity. It is the main reason why the society owes him full attention and care. Thus, to avoid both disproportionate therapeutic obstinacy and premature abandonment, the PACP-PEPI follows seven steps.

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Step 1 – Early identification and multidisciplinary team activation

- When: Immediately upon diagnosis of high-risk severe prematurity (<27 weeks).
- Who: multidisciplinary care team that includes neonatologists, obstetricians, nurses, psychologists, chaplains (when requested), mediator (if needed for language or culture purposes, preferably educated/trained in bioethics, or ideally a bioethicist) and trained parents (64).
- Goal: Assemble a multidisciplinary care team to ensure that the EPI's dignity and the family's needs are addressed from the outset.

Personalist anchor: Recognition of the EPI as a subject of care, not an object of intervention.

Step 2 – Transparent prognostic communication

- When: Before birth (if possible) and immediately after delivery.
- Who: Lead physician with psychologist or counselor present, chaplains (when requested), and a mediator (if needed for language or culture purposes, preferably educated/trained in bioethics, or ideally a bioethicist)
- Goal: Provide parents with clear, compassionate, and honest information regarding prognosis, possible interventions, and likely outcomes (65).

Personalist anchor: Truth-telling (52, p. 150, 364) *as a foundation of the EPI's best interests, as a form of respect for parental responsibility* (52, p. 411) *and the relational dignity of decision-making* (52, p. 216).

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Step 3 – Shared Relational Dialogue

– What: Structured family-team meetings (66)multidisciplinary family meetings (TMFM to discuss treatment options + mediator (if needed for language or culture purposes, preferably educated/trained in bioethics, or ideally a bioethicist)
– Process:
  • Parents express values, hopes, fears and expectations;
  • Clinicians provide clinical perspectives without imposing decisions;
  • Cultural or spiritual beliefs are acknowledged and respected.

Personalist anchor: Emphasis on communion/communication since decisions are relational acts grounded in the dignity of both EPI and parents.

Step 4 – Personalist Advance Care Planning Document

– What: A written plan developed jointly by parents and the medical team after the first or the second family-team meeting.
– Content:
  • The EPI's medical condition and prognosis;
  • Agreed principles (life protection, proportionality, non-abandonment);
  • Specific decisions regarding resuscitation, intensive care, and thresholds for transitioning to palliative care;
  • Signature of parents, lead physician, and ethics committee (if involved).
– This document is not set in stone. Parents should have every right to modify it at any time.

Personalist anchor: Written commitment ensures fidelity to dignity and relational responsibility over time

Step 5 – Ethics Committee Consultation (If needed)

– When: In cases of disagreement, moral uncertainty, or culturally complex scenarios.

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– Who: Ethics Committee with representation from medicine, nursing, ethics, law, pastoral/spiritual care and bioethicist (the latter can also play the role of mediator if needed for language or culture purposes)
– Goal: Offer ethical guidance and facilitate dialogue; not to impose binding decisions.

Personalist anchor: Support conscience formation, ensuring dignity remains central despite plural cultural perspectives.

Step 6 – Proportionality Assessment

– Criteria to evaluate interventions:
  • Is there reasonable hope of recovery or survival?
    ▪ Therapeutic principle
    ▪ Double effect principle: Burden to the EPI – Does the intervention impose disproportionate suffering with little benefit?
  • Alternatives: is palliative care more consistent with the EPI's dignity?

Personalist anchor: The principle of proportionality, avoiding both nihilism (denying treatment based on prognosis alone) and vitalism (insisting on aggressive treatment regardless of burdens).

Step 7 – Continuous Review and Flexibility

– When: According to clinical progression (e.g., stabilization, complications, or developmental changes).
– Who: Same multidisciplinary team with parental input.
– Goal: Adapt the plan to evolving realities without undermining the principle of dignity.

Personalist anchor: Ethical fidelity requires both consistency and openness to change as new information arises.

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b. *Innovation Keys*

This PACP-PEPI has two innovative keys:

i. *The "Dignity Check"*

At each step, the team asks a central guiding question: **"Does this option affirm and protect the intrinsic dignity of the EPI as a person?"**

This operationalizes personalist ethics into a concrete evaluative tool for clinical decision-making.

ii. *Supportive Care for Parents and Health Staff*

At each step, a Supportive Care for Parents and Staff must be ensured to provide psychological, spiritual, and social support for families, but also to debrief the staff to prevent burnout for both parents (67,68) and health staff (69–71). The dignity of the infant radiates outward, demanding care for all relational actors involved in the decision-making process.

5. Conclusion

The PACP-PEPI transforms abstract ethical principles into actionable steps for neonatal intensive care. It offers a structured process –anchored in human dignity, relational dialogue, and proportionality– that can guide parents, physicians, and ethics committees in making ethically sustainable decisions. By adopting the personalist approach and embedding the "dignity check" into every stage, hospitals can ensure that the most vulnerable patients, severely preterm infants, receive care that respects their humanity and fosters solidarity. In addition, it is also possible to reduce, or even eliminate, the "moral distress" that afflicts healthcare personnel in their daily decisions

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when caring for critical patients such as extremely premature newborns. This will increase the quality of care for newborns and the quality of work.

Like any model, the PACP-PEPI model is not a perfect one. Nevertheless, it could meet expectations, especially if it considers some implementation considerations:

- Training programs for physicians and nurses in personalist ethics and communication skills.
- Integration of PACP-PEPI into neonatal intensive care unit (NICU) policies.
- Research and data collection on outcomes (clinical, parental satisfaction, ethical coherence).

A field study is required to assess the effectiveness and value of this model.

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