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JUNE 24-25 2024

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## Ethical decisions during ECMO

Bénédicte Gaillard-Le Roux

Pediatric intensive care unit, CHU Nantes

24/06/2024



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# CONFLICTS OF INTEREST

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Fresenius: consultant

- **Life-saving support tool but significant morbidity and mortality**
  - Survival rate: 40-65% (ELSO registry)
  - Morbidity:
    - Primarily neurological
      - Ischemic or hemorrhagic strokes
      - Increased risk of disability, neurodevelopmental disorders, and impaired quality of life

## INTRODUCTION: Why does ECMO raise ethical questions?

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- Life-saving support tool but significant morbidity and mortality
- **Expanding number of conditions and indications or « relative » contraindications** (immunocompromised patients)
  - The urgent decision-making process for ECMO initiation can sometimes be challenging

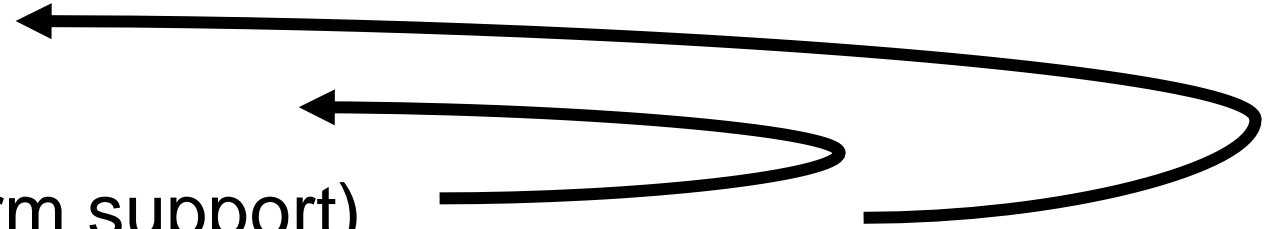
# WHY DOES ECMO RAISE ETHICAL QUESTIONS?

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- Life-saving support tool but significant morbidity and mortality
- Expanding number of conditions and indications or « relative » contre-indications
- **The availability of resources**
- **Mobilisation of human resources**
- **Time factor influences effectiveness**
- **Relationship between experience and performance**
- **Costly treatment**
- **Environmental impact**

# ETHICAL QUESTIONS DURING ECMO

- ECMO = transient support:
  - Bridge to recovery
  - Bridge to transplantation
  - Bridge to bridge (long term support)



But sometimes

- Death
- Bridge to nowhere...
  - Unreasonable obstinacy

# WHAT ARE THE ETHICAL ISSUES SURROUNDING ECMO?

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- What are the criteria and timing for determining the 'futility' of a medical intervention in case of neurologic complications?
- **Bridge to nowhere**
  - What are the criteria and timing for deciding when to discontinue ECMO support?
- Should the decision to continue or to discontinue ECMO be a shared decision or should clinicians alone decide when to stop?
- How do we effectively manage disagreements or conflicts with parents regarding end-of-life decisions for their child on ECMO?
- How can we address the moral distress experienced by healthcare providers involved in the child's care?



# ETHICAL PRINCIPLES BY BEAUCHAMP AND CHILDRESS



- **Principle of self-determination or autonomy**

Respecting the child and his parents: respectful communication, information sharing, and active listening



- **Principle of causing no loss or doing no harm (non-maleficence)**

Primum non nocere. If ECMO cannot or is no longer accomplishing benefit, it may be stopped



- **Principle of beneficence:**

The child's best interest should always be the cornerstone of our discussions



- **Principle of equity (justice):**

Devoting the same attention to each situation, regardless of the relationships with the child and family, and regardless of the composition of the healthcare team that is present.

## Parental experience of highly technical therapy: Survivors and nonsurvivors of extracorporeal membrane oxygenation support

Pediatr Crit Care Med 2003 Vol. 4, No. 2

Martha A. Q. Curley, RN, PhD, CCNS, FAAN; Elaine C. Meyer, RN, PhD

Table 1. Multidisciplinary intensive care unit patients supported on extracorporeal membrane oxygenation (1990–1998)

	Total ( <i>n</i> = 327)		Survivors ( <i>n</i> = 204)		Nonsurvivors ( <i>n</i> = 123)	
	<i>n</i>	(%)	<i>n</i>	(%)	<i>n</i>	(%)
Newborn medical	147	(45)	123	(84)	24	(16)
Newborn surgical	75	(23)	31	(41)	44	(59)
Newborn cardiac	22	(6)	8	(36)	14	(64)
Pediatric medical	26	(8)	17	(65)	9	(35)
Pediatric surgical	10	(3)	4	(40)	6	(60)
Pediatric cardiac	47	(14)	21	(45)	26	(55)

- 22% had been informed about the possibility of death prior to consent
- Over 50% of parents felt they had no choice but to consent to ECMO,
- 72% of parents of children who died after ECMO would have consented to the procedure again

## Decision-Making, Ethics, and End-of-Life Care in Pediatric Extracorporeal Membrane Oxygenation: A Comprehensive Narrative Review

Katie M. Moynihan, MBBS<sup>1-3</sup>

Anna Dorste, MLIS<sup>4</sup>

Bryan D. Siegel, MD<sup>1,2</sup>

Edon J. Rabinowitz, MD<sup>5</sup>

Andrew McReynolds, MD<sup>6</sup>

Tessie W. October, MD, MPH<sup>7</sup>

PCCM 2021

### B Conversation Principles for Pediatric ECMO



#### Informed consent

- Honest information provision
- Transparency surrounding risks, benefits, limitations and uncertainty in outcomes



#### Setting goals early

- Define the intended goal of ECMO support (including fetal), setting clear expectations for ECMO as temporary and supportive, not curative
- Potential need to stop ECMO in the absence of successful achievement of the broad purpose



#### Timelines and milestones

- Timelines for reassessing benefits and burdens
- Defining milestones that represent progress or worsening status



#### Reevaluation

- Frequent reevaluation of treatment goals using realistic evidence-based projections for meaningful survival weighed with burdens
- Reassessment if goals or milestones are being met



#### Support

- Establishing trust, rapport and a supportive environment and therapeutic relationship for shared decision-making
- Consideration of early subspecialty palliative care or ethics committee referral with conflict



#### Eliciting values

- Sharing worries and ascertaining family values, hopes and fears, and preferences including for participation at end-of-life



#### Provision of goal-aligned care

- A key consideration in discontinuation is if the goals for which ECMO was initiated are achievable
- Respecting and supporting families through decisions contrary to clinicians' personal opinions unless perceived to be misaligned with the child's best interests



#### Recommendations

- Providing value-aligned recommendations for discontinuation
- Avoiding placing burden on families through reassurance that they and team have done everything possible

# A Communication Guide for Pediatric Extracorporeal Membrane Oxygenation

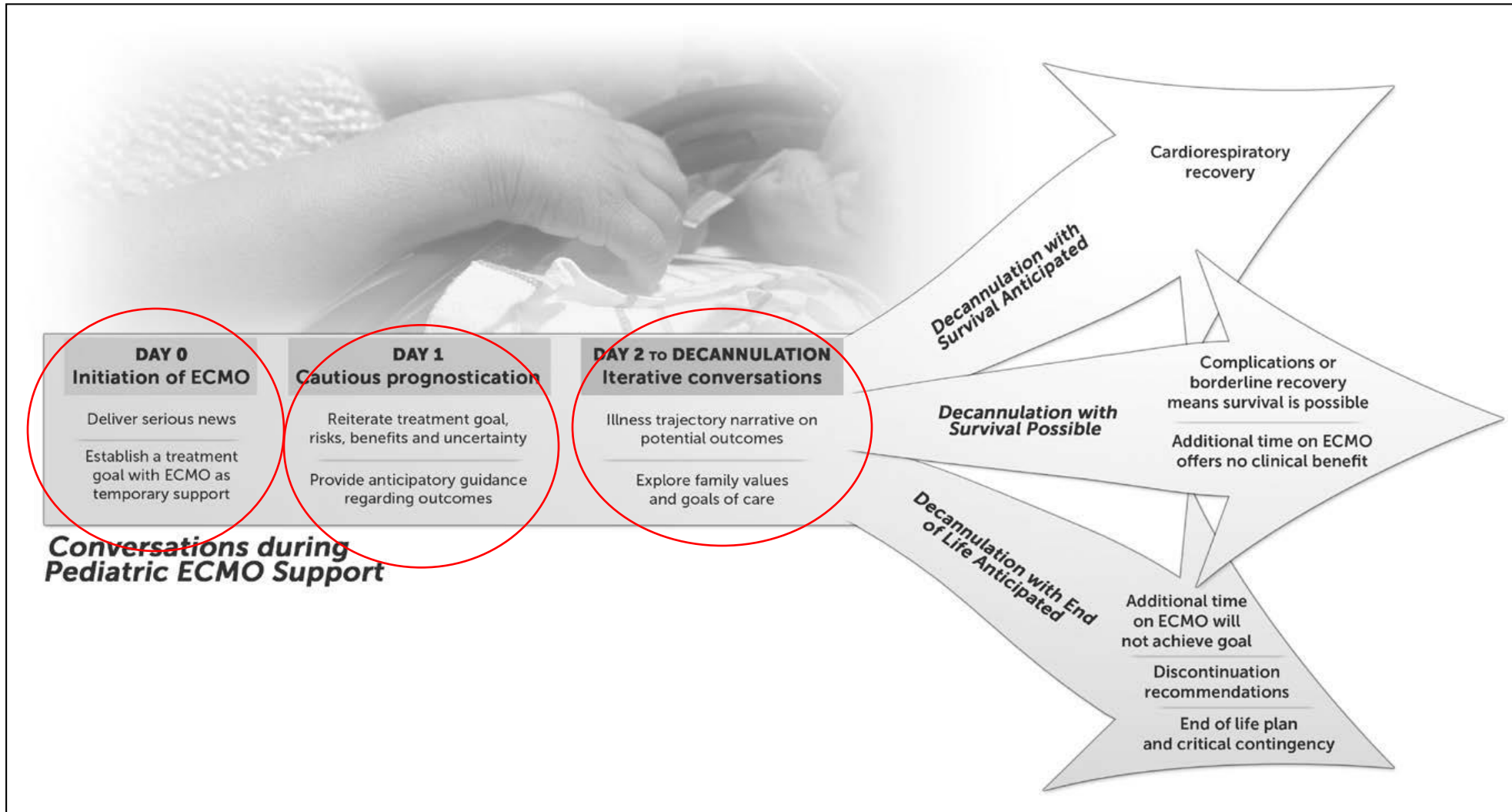
Katie M. Moynihan, MBBS<sup>1-3</sup>

Nick Purol, MSW<sup>4,5</sup>

Peta M. A. Alexander, MBBS<sup>1,2</sup>

Joanne Wolfe, MD<sup>2,4,5</sup>

Tessie W. October, MD, MPH<sup>6</sup>



**Figure 1.** A framework for structured, transparent conversations during pediatric extracorporeal membrane oxygenation (ECMO) support.

# HOW TO AVOID CONFLICT WITH PARENTS?

Withholding and withdrawing treatment in pediatric intensive care.  
Update of the GFRUP recommendations

R. Cremer<sup>a,\*</sup>, L. de Saint Blanquat<sup>b</sup>, S. Birsan<sup>c</sup>, F. Bordet<sup>d</sup>, A. Botte<sup>c</sup>, O. Brissaud<sup>c</sup>,  
J. Guilbert<sup>e</sup>, B. Le Roux<sup>f</sup>, C. Le Reun<sup>g</sup>, F. Michel<sup>h</sup>, F. Millasseau<sup>f</sup>, M. Sinet<sup>e</sup>, P. Hubert<sup>b</sup>  
on behalf of GFRUP

<sup>a</sup>Réanimation et soins continus pédiatriques, hôpital Jeanne-de-Flandre, ERER des Hauts-de-France, CHU de Lille, 59037 Lille, France

<sup>b</sup>Réanimation pédiatrique, hôpital Necker-Enfants-malades, 149, rue de Sévres, 75015 Paris, France

<sup>c</sup>Unité de soins continus et réanimation néonatale et pédiatrique, hôpital des enfants, CHU Bordeaux, place Amélie-Raba-Léon, 33000 Bordeaux, France

<sup>d</sup>Réanimation pédiatrique, hôpital Femme-Mère-Enfant, hospices civils de Lyon, 59, boulevard Pinel, 69500 Lyon-Bron, France

<sup>e</sup>Réanimation néonatale pédiatrique, hôpital Armand-Trousseau, 26, avenue du Docteur-Arnold-Netter, 75012 Paris, France

<sup>f</sup>Réanimation pédiatrique, CHU de Nantes, 1, place Alexis-Ricordeau, 44000 Nantes, France

<sup>g</sup>Réanimation pédiatrique, hôpital Clocheville, CHU de Tours, 2, boulevard Tonnelie, 37000 Tours, France

<sup>h</sup>Anesthésie et réanimation pédiatrique, hôpital de la Timone, 264, rue Saint-Pierre, 13385 Marseille cedex 5, France

<sup>i</sup>Réanimation et surveillance continue pédiatriques, hôpital Robert-Debré, 48, boulevard Sérurier, 75019 Paris, France

- Disagreement can enrich the dialogue
- Relational communication based on empathy and respect
- Child-centered decision making

Suggested measures to resolve conflicts with families [11,30,47,49].

When there is a persistent conflict

Give the parents a letter from the physician in charge that provides a simple explanation of what is at stake and of the reasons that prompted the decision proposed to them; this can help the parents discuss the issue with one another and with their close family and friends

Suggest obtaining the assistance of a psychologist, child psychiatrist, or ethno-psychiatrist to explore and attempt to understand how the parents function

Suggest that the parents meet with the head of the department

Perhaps suggest a change of the physician in charge

Ask for a second opinion, even based only on the patient's files

Obtain the involvement of a mediator

Ask, provided the parents agree, for advice from an ethics committee

R. Cremer<sup>a,\*</sup>, L. de Saint Blanquat<sup>b</sup>, S. Birsan<sup>c</sup>, F. Bordet<sup>d</sup>, A. Botte<sup>c</sup>, O. Brissaud<sup>c</sup>,  
J. Guilbert<sup>e</sup>, B. Le Roux<sup>f</sup>, C. Le Reun<sup>g</sup>, F. Michel<sup>h</sup>, F. Millasseau<sup>f</sup>, M. Sinet<sup>e</sup>, P. Hubert<sup>b</sup>  
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<sup>a</sup>Réanimation et soins continus pédiatriques, hôpital Jeanne-de-Flandre, ERER des Hauts-de-France, CHU de Lille, 59037 Lille, France

<sup>b</sup>Réanimation pédiatrique, hôpital Necker-Enfants-malades, 149, rue de Sèvres, 75015 Paris, France

<sup>c</sup>Unité de soins continus et réanimation néonatale et pédiatrique, hôpital des enfants, CHU Bordeaux, place Amélie-Raba-Léon, 33000 Bordeaux, France

<sup>d</sup>Réanimation pédiatrique, hôpital Femme-Mère-Enfant, hospices civils de Lyon, 59, boulevard Pinel, 69500 Lyon-Bron, France

<sup>e</sup>Réanimation néonatale pédiatrique, hôpital Armand-Trousseau, 26, avenue du Docteur-Arnold-Netter, 75012 Paris, France

<sup>f</sup>Réanimation pédiatrique, CHU de Nantes, 1, place Alexis-Ricordeau, 44000 Nantes, France

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<sup>i</sup>Réanimation et surveillance continue pédiatriques, hôpital Robert-Debré, 48, boulevard Sérurier, 75019 Paris, France

S. Dager<sup>a,i,\*</sup>, S. Blanot<sup>b,c</sup>, A. Deho<sup>a,d</sup>, J. Beaux<sup>e</sup>, F. Bonnin<sup>b</sup>, F. Bordet<sup>f</sup>, R. Cremer<sup>g,h</sup>, S. Dupont<sup>d</sup>,  
A. Klusiewicz<sup>j</sup>, A. Lafargue<sup>k</sup>, M. Lemains<sup>l</sup>, F. Michel<sup>l</sup>, R. Quéré<sup>o</sup>, L. de Saint Blanquat<sup>m</sup>,  
M. Samyn<sup>l</sup>, M.-L. Saulnier<sup>n</sup>, L. Temper<sup>o</sup>, Z. Merchaoui<sup>i,p</sup>, B. Gaillard-Le Roux<sup>q</sup>,  
Groupe-Francophone-de-Réanimation-et-Urgences-Pédiatriques-(GFRUP)<sup>a</sup>,  
Association-des-Anesthésistes-Réanimateurs-Pédiatriques-d'Expression-Française-  
(ADARPEF)<sup>a</sup>

- Discussion:
  - Collegial procedure in France
  - Unreasonable obstinacy?
  - Shared decision-making with parents: physicians should let the parents choose their level of involvement
  - Implementation of a new care plan
- How? Parameters of ECMO can be decreased gradually or the assistance can be stopped
- Discuss controlled donation after circulatory death (cDCD)

# MORAL DISTRESS FOR HEALTHCARE PROVIDERS



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Triggers of experience of moral distress:

- The seemingly lack of honest and transparent communication with parents;
- The apparent loss of situational awareness among doctors;
- The perceived lack of recognition for the role of nurses and the variability in end-of-life decision-making;

Between hope and disillusionment

ECMO seen through the lens of nurses working in a neonatal and paediatric intensive care unit

Jovana A. Jucker<sup>1</sup> | Vincenzo Cannizzaro MD, PhD<sup>2,3,4</sup>  |  
Roxanne E. Kirsch MD<sup>5,6</sup> | Jürg C. Streuli MD, PhD<sup>1,4,7</sup> | Eva De Clercq PhD<sup>1,7</sup> 

Nurs Crit Care. 2024;1–12.

# PREVENTIVE ETHICS

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- Importance of ethical climate
  - Relationship between ethical climate perception and moral distress
  - Daily interdisciplinary rounds
  - Open communication among team members
  - Mutual respect between nurses and physicians
- Information and open communication with parents
  - Family centered-care
  - Discussion of values appropriate goals and fears
  - Shared decision-making
  - Involving external support if necessary (pediatric palliative care team, psychologist, religious representative, ethics committee)



# CONCLUSION

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- Ethical considerations during pediatric ECMO are complex and multifaceted
- Information and open communication are crucial
- Keep always the child at the center
- Embrace uncertainty and bear the weight of decision-making

THANK YOU FOR YOUR ATTENTION