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Insuficiência Respiratória: aspectos éticos

Hospital Pediátrico Coimbra

Alexandra Dinis

Doença crónica complexa

- Nº crescente de admissões em UCIP
- Objetivo: retorno à linha de base
- Famílias impreparadas
 - Sem diagnóstico definido
 - Sem prognóstico bem delimitado
 - Esperança de vida? ... longa
- Podem beneficiar do nível de cuidados de uma UCIP

Suporte respiratório

- IRA
- IR Crónica agudizada
 - admissão em cuidados intensivos
 - início ou retirada de VM
 - decisões de não entubação / reentubação
 - decisões quanto a ventilação de longa duração traqueostomia/VNI
 - criança dependente de tecnologia suporte de vida

End-of-Life Practices Among Tertiary Care PICUs in the United States: A Multicenter Study

Kathleen L. Meert, MD¹; Linda Keele, MD²; Wynne Morrison, MD³; Robert A. Berg, MD³; Heidi Dalton, MD⁴; Christopher J. L. Newth, MD, FRCPC⁵; Rick Harrison, MD⁶; David L. Wessel, MD⁷; Thomas Shanley, MD⁸; Joseph Carcillo, MD⁹; Amy Clark, MS¹⁰; Richard Holubkov, PhD¹⁰; Tammara L. Jenkins, MSN, RN¹¹; Allan Doctor, MD¹²; J. Michael Dean, MD¹⁰; Murray Pollack, MD⁴; and the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development Collaborative Pediatric Critical Care Research Network

Pediatric Critical Care Medicine

September 2015 • Volume 16 • Number 7

3 anos: 10078 admissões - 252 óbitos

68% dos doentes tiveram suspensão ou limitação terapêutica.

72% dos doentes que morreram tinham doença crónica previa à admissão na UCI.

63% - discussão sobre decisão terapêutica

Mechanical ventilation for respiratory failure in children with severe neurological impairment: is it futile medical treatment?

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22 crianças - deficit neurológico grave

Outcome 1 ano

- 11 óbitos
- 11 sobreviventes
 - 6 extubadas na 1ª tentativa, sem readmissões em UCIP

Children and Young Adults Who Received Tracheostomies or Were Initiated on Long-Term Ventilation in PICUs*

Jeffrey D. Edwards, MD, MA, MAS¹; Amy J. Houtrow, MD, PhD, MPH²; Adam R. Lucas, PhD³; Rachel L. Miller, MD^{4,5}; Thomas G. Keens, MD⁶; Howard B. Panitch, MD⁷; R. Adams Dudley, MD, MBA^{8,9}

Pediatr Crit Care Med. 2016 Aug;17(8):e324-34

73 PICU - 115 437 doentes

1,8% Traq ou Ventilação Longa Duração na UCI

72% - admissões urgentes, doença crítica aguda ou crónica agudizada

90% - “substantial chronic conditions and comorbidities”

- 50% “moderate or worse cerebral disability upon discharge”
- 20% dos doentes com VI e 16% dos doentes em VNI tiveram alta para instituições ou centros de reabilitação

“

Tracheostomies and Long-Term Ventilation in Children: Are We Being Thoughtful and Consistent?*

“melhor interesse para a criança”

??? o menor dos males

1 – Processo de decisão

2 – Envolvimento parental

. considerações éticas e enquadramento legal

Tracheostomies and Assisted Ventilation in Children With Profound Disabilities: Navigating Family and Professional Values

PEDIATRICS Volume 133, Supplement 1, February 2014

VIEWPOINT

Ethical considerations in paediatric neurology: Neuromuscular disease and epilepsy

John B Bodensteiner and Yu-Tze Ng

Division of Pediatric Neurology, Barrow Neurological Institute/St. Joseph's Children's Health Center, Phoenix, Arizona, United States

Journal of Paediatrics and Child Health 47 (2011) 599–602

- The underlying concern is whether a life with profound disabilities is a life worth living
- Life from both the families and the child's perspective could be meaningful
- Many clinicians seem to place a high value on cognitive functioning and independent living, a value that not all parents of children with profound disabilities share.
- A persistent concern is that parents want life sustaining interventions for their own needs and interests.

Processo de decisão partilhada

Consentimento informado

- Postura paternalista, protetora

“Forgoing life-sustaining treatments. How the decision is made in French pediatric intensive care units. “

“ a autonomia parental na UCI é uma ilusão”

“ culpa” “ responsabilização”

“Parents should not be excluded from decisions to forgo life-sustaining!”

Crit Care Med 2001

Conflito

When parents say “more” and health care professionals say “enough”

Dawn Davies MD MA FRCPC^{1,2}, Cheryl Mack MD MA FRCPC³

Paediatr Child Health Vol 20 No 3 April 2015

Questão – há limites para o que os pais querem?



- Justiça
 - Acesso equitativo a cuidados de saúde
 - Não discriminação
 - Recursos limitados
 - Vulnerabilidade

Guia sobre o processo de decisão
relativo a tratamentos médicos
em situações de fim de vida



os médicos

- têm de se **abster** de dispensar tratamentos que sejam **inúteis** ou **desproporcionados** face aos riscos e constrangimentos que possam induzir.
- têm de prover aos doentes tratamentos proporcionados e adaptados à sua situação
- têm o dever de **cuidar dos seus doentes, atenuar o seu sofrimento e** mostrar-se solidários.

É t i c a

- Autonomia não implica o direito a receber todo e qualquer tratamento que o doente possa exigir, designadamente quando o tratamento em causa é considerado desadequado.



- Obrigação de apenas prestar tratamento apropriados
 - 1º indicação médica
 - 2º ser apropriado

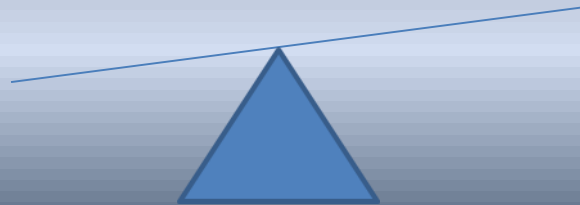
Tratamento fútil



Tratamento potencialmente inapropriado

Benefício global

Beneficiência / Não maleficiência



Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice

Vic Larcher,¹ Finella Craig,² Kiran Bhogal,³ Dominic Wilkinson,⁴ Joe Brierley,^{1,5}
on behalf of the Royal College of Paediatrics and Child Health

Larcher V, et al. *Arch Dis Child* 2015;**100**(Suppl 2):s1–s23.

1. This document sets out circumstances under which withholding or withdrawing life sustaining treatment **might be** ethically permissible—**NOT** circumstances under which such treatment **must certainly be** withheld or withdrawn.
2. The document describes situations in which **individual children** should be spared inappropriate invasive procedures—**NOT types of children** to whom appropriate procedures should be denied.

When life is limited in quantity

If treatment is unable or unlikely to prolong life significantly it may not be in the child's best interests to provide it:

1. Brain stem death
2. **Imminent death**, where physiological deterioration is occurring irrespective of treatment
3. **Inevitable death**, where death is not immediately imminent but will follow and where prolongation of life by LST confers no overall benefit.

When life is limited in quality

Situations where treatment **may be able to prolong life significantly** but will not alleviate the burdens associated with illness or treatment itself:

1. **Burdens of treatments**, where the treatments themselves produce sufficient pain and suffering so as to outweigh any potential or actual benefits
2. **Burdens of the child's underlying condition**. Here the severity and impact of the child's underlying condition is in itself sufficient to produce such pain and distress as to overcome any potential or actual benefits in sustaining life
3. **Lack of ability to benefit**; the severity of the child's condition is such that it is difficult or impossible for them to derive benefit from continued life.

An Official ATS/AACN/ACCP/ESICM/SCCM Policy Statement: Responding to Requests for Potentially Inappropriate Treatments in Intensive Care Units

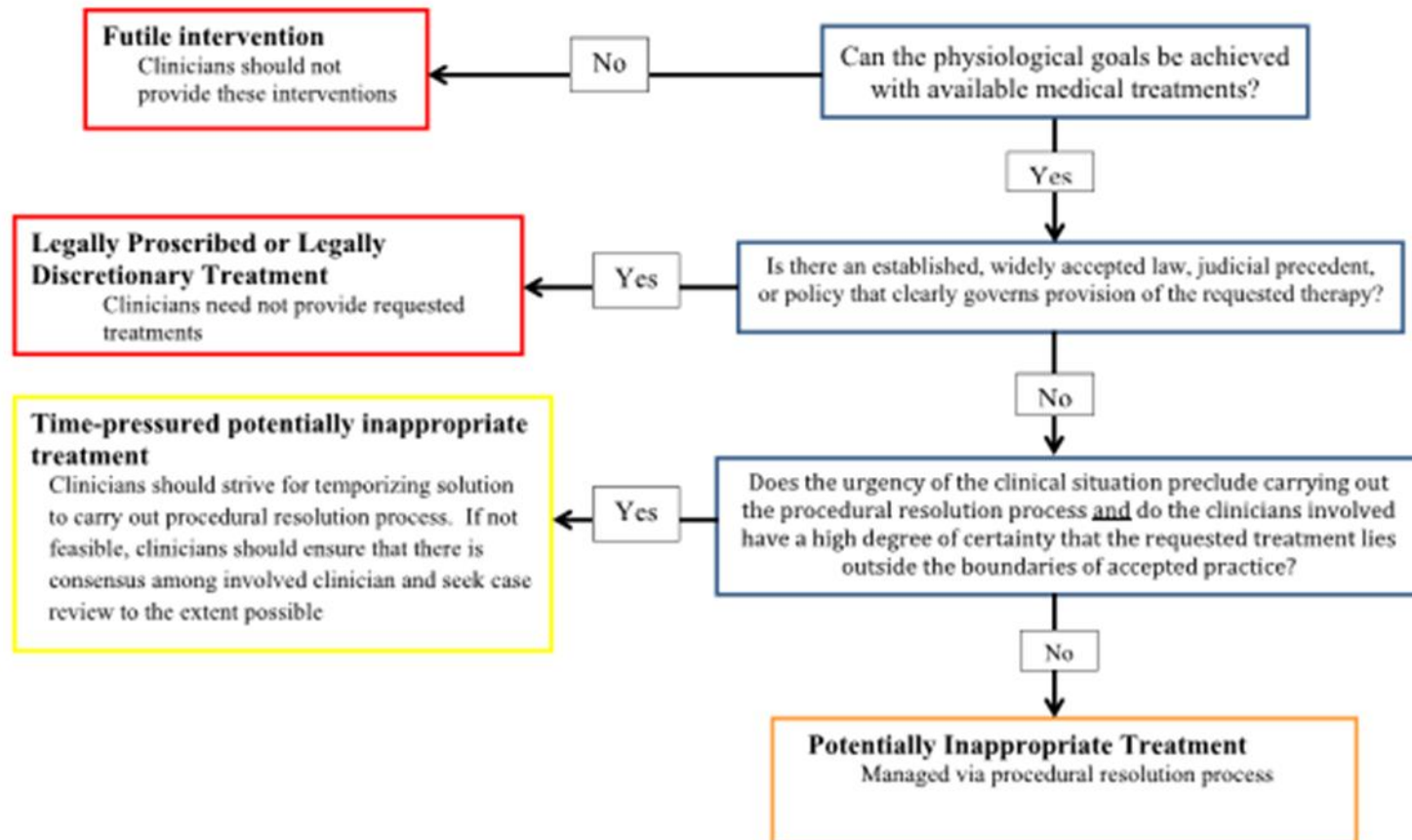
Table 3. Categories of Disputed Treatments in Intensive Care Units

Category	Definition	Conflict-Resolution Process	Examples
Requests for potentially inappropriate treatment	Treatments that have at least some chance of accomplishing the effect sought by the patient or surrogate and are not proscribed, but clinicians believe that competing ethical considerations justify refusing to provide the requested treatment	Conflict resolution should be accomplished via the process outlined in recommendation 3 and in Table 4.	3. A clinician believes it is inappropriate to continue mechanical ventilation in a patient with widely metastatic cancer. 4. A clinician believes it is inappropriate to place a tracheostomy tube in a child with prolonged respiratory insufficiency and severe irreversible neurological impairment.

Preventing conflict: **communication** as cornerstone

An Official ATS/AACN/ACCP/ESICM/SCCM Policy Statement: Responding to Requests for Potentially Inappropriate Treatments in Intensive Care Units

Am J Respir Crit Care Med 2015Jun; 191(11):1318-30



How should clinicians respond to requests for potentially inappropriate treatment?

Intensive Care Med 2016 Mar;42(3):422-5

**Table 5. Questions to Assist in
Illuminating Moral Issues in
Time-pressured Situations**

Am I certain that this requested treatment
is outside of the boundaries of accepted
practice?

Would I be willing to have the rationale for
my decision publicly reviewed in an
appeals board or court?

What are the consequences to the patient,
surrogate, team, or institution as a result
of implementing this decision?

Am I sure that sex, race, socioeconomic
status, ability to pay, or other
psychosocial factors are not entering into
my decision?

Suspensão da ventilação

- Protocolos?

The Durban World Congress Ethics Round Table Conference Report: III. Withdrawing Mechanical ventilation--the approach should be individualized. J Crit Care. 2014 Dec;29(6):902-7.

Não usar relaxantes musculares !

Extubação em casa

- **Home extubation by a pediatric critical care team: providing a compassionate death outside the pediatric intensive care unit.** *Pediatr Crit Care Med.* 2010;11(3):401-3.
- **Pediatric Critical Care Transport as a Conduit to Terminal Extubation at Home: A Case Series.** *Pediatr Crit Care Med.* 2016; Oct 28 doi: 10.1097/PCC.0000000000000997

"We want everything done"

Arch Dis Child 2008;**93**:192–193.
doi:10.1136/adc.2007.120568

limitação terapêutica

NÃO É

limitação de cuidados