Fostering Dysthanasia: The Universal “Opt-Out” Approach to CPR

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Focus of scholarship

• Overall interest: Ethical considerations in the provision of pediatric critical care medicine

• Primary interest: Complex medical decision making regarding the utilization and limitation of life saving interventions
  • Cardiopulmonary resuscitation (CPR)
  • Extracorporeal life support (ECLS or ECMO)
  • Organ donation and transplantation
Clinical Vignette

- 6 year old boy
- Undefined progressive neurodegenerative disorder
- Chronic respiratory failure, on BiPAP
- Daily episodes of bradycardia to the 30s, requiring 1-2 minutes of CPR
- On admission to PICU:
  - Mother requests “everything be done” for her son
Clinical Vignette

• New PICU attending each week addresses code status:
  • Do you still want full resuscitation?
  • Yes, I want everything done for my child. How could I not?

• Moral distress among medical providers in ICU increases

• Private discussions regarding “slow codes” evolve

• Tension develops between healthcare team and mother as she expresses extreme struggle with the decision to “end her child’s life”
Ethical Issue

*Dying* children and their families are potentially harmed when the presumption of consent to cardiopulmonary resuscitation (CPR) applies to all hospitalized children, regardless of prognosis and the likely efficacy of CPR.

“Opt-out” approach to CPR potentially fosters a culture of *dysthanasia*: exaggerated *prolongation* of agony, suffering, and death of the patient with *futile* and *useless* treatment

Clark, Dudzinski *Pediatrics* 2013
Sorta-Bilajac; *Medicinski Arhiv* 2005
Research Objectives

• Review the historical evolution of cardiopulmonary resuscitation and do-not-attempt-resuscitation (DNAR) orders

• Justify why the current “opt-out” approach to cardiopulmonary resuscitation is potentially harmful and potentially disrespectful to dying pediatric patients and their families

• Demonstrate how an informed assent approach to limitation of resuscitation discussions improves the quality of end of life care for pediatric patients
Normative Analysis: Background Research

• History and current status of:
  • Cardiopulmonary resuscitation
  • Limitation of resuscitation orders
  • Medical futility
  • Legal cases regarding the limitation of resuscitation

• Palliative care medicine
  • History and current practice
  • Tools including goal oriented approach to communication
Presumptive Universal Consent to CPR: The Opt-Out Approach

- **1960s- CPR**
- **1974- DNR**
- **1980s- DNAR, AND**

**PARENTAL CONSENT** to FORGO CPR

How to guide medical care

Improve quality of life and reduce suffering

Provide high quality services

Fig. 1. Palliative care and its three core domains of tasks.

Feudtner Ped Clin N Amer 2007
Normative Analysis: Development and Justification of an Argument

• Attempting CPR is not appropriate in all medical circumstances

• Universal “opt-out” approach to CPR is harmful and potentially disrespectful to dying children and their families

• Physicians have a moral and professional responsibility to protect dying children and families from harm
Normative Analysis

Attempting CPR is not appropriate in all medical circumstances, particularly in dying children

- **Intended therapeutic goal of CPR** = To restore circulation to vital organs so underlying proximal and distal causes of cardiac arrest can be treated

- **Futile CPR** = Attempting CPR that will not achieve its intended therapeutic goal or will merely prolong the dying process

- **Dying children** = children for which there is consensus among involved health care providers that attempting CPR would be futile
Normative Analysis

Universal “opt-out” approach to CPR is harmful and potentially disrespectful to dying children and their families

- Ignores intimacy and emotional complexity of parent-child relationship
- Promotes the use of slow codes and show codes
- Increases health care provider moral distress which harms physician-patient-parent relationship
- Potentially causes direct physical harm to child if futile CPR is attempted
Intimate Parent-Child Relationship

- Parental Identity and Integrity
- Parental Loss of Control
- Parental Sense of Guilt
- Parental Hope for Survival
- Childhood Deaths are “Unnatural”

Normative Analysis

Physicians have a moral and professional responsibility to protect dying children and families from harm.

Physicians have a duty to make both medical and value-based decisions.
Solution: Informed Assent Using Goal-Directed Approach to Code Status Discussions

- Parental Goals
- Physician Advice
- High Quality of Death

Menu of Non-Therapeutic Options

Impact of Research/ Scholarly Work

• Peer-reviewed publications:


• Invited national presentations:

Fostering Dysthanasia: Attempting CPR in Terminally Ill Children; Peds PLACE Webinar, Little Rock AK, Oct 2013

The Culture of Dysthanasia: Attempting CPR in Terminally Ill Children; Children’s Mercy Bioethics Series Webinar, Kansas City MO, Mar 2014

Fostering Dysthanasia: The Universal “Opt-Out” Approach to CPR; Memorial Children’s Hospital Grand Rounds and Regional Palliative Care Conference, Long Beach CA, Oct 2014
Impact of Research/ Scholarly Work

• **Local administrative work**
  
  • SCH End of Life Work Group, Co-chair
  
  • SCH policy development and implementation: Limitation of Resuscitation Documentation and Orders
  
  • SCH order set implementation: Code Status
  
  • SCH Educational Sessions:
    
    • Seattle Children’s Hospital Grand Rounds
    
    • Break out sessions for nurses, child life specialists, social workers, and physicians
Future Directions

• Perform empirical chart review:
  • Pre/post implementation of hospital policy and modified order set
• Provide ongoing education, locally and nationally
• Provide ongoing modifications to SCH policies regarding end of life care
• Consider obtaining additional training in pediatric palliative care medicine
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