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## At the coalface – medical ethics in practice

# Futility and death in paediatric medical intensive care

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### Abstract

*We have conducted a retrospective study of deaths on a paediatric medical intensive care unit over a two-year period and reviewed similar series from outside the UK. There were 89 deaths out of 651 admissions (13.7% mortality). In almost two-thirds of the cases death occurred with a decision to limit medical treatment or withdraw mechanical ventilation, implying that additional or further therapy was considered futile. We highlight this as a crucially important issue in the practice of intensive care. More comprehensive studies are needed to help clinicians derive consensus on what constitutes a futile intervention, and therefore when such an intervention should be withheld. This will help families and society better understand the limitations of intensive care.*

### Introduction

It is over 20 years since Duff and Campbell initiated an important debate about ethical dilemmas encountered when caring for preterm babies.<sup>1</sup> As intensive care has developed and expanded into a wider paediatric practice these issues have remained pertinent, particularly as young patients are unable to express their wishes with regard to treatment or non-treatment. Unfortunately, progress in our ability to provide extraordinary life-sustaining therapy has made defining the limits of intensive care even harder. Ethical issues arise when a doctor is asked to treat a child with an underlying lethal disease who requires mechanical ventilation for an acute deterioration; or when treating a previously well child who, although expected to survive, may be left severely debilitated or trapped in a mentally limited and painful existence.

We have therefore undertaken the first review focusing on death after withdrawal or limitation of treatment in a British paediatric medical intensive care unit (PICU). The aim was to identify how often life-sustaining therapy was withheld or withdrawn

and thus highlight the limits of intensive care. This description of current practice would serve as a basis for further study.

### Patients and methods

Our paediatric medical intensive care unit functions within a children's hospital, accepting patients for acute emergency care from casualty departments, paediatric units, intensive care units, and a variety of subspecialist wards within our own hospital. Our practice can be categorised into acute respiratory disease (50%), acute brain disease (34%) and sepsis syndrome or multiple organ system dysfunction (14%).

We have conducted a retrospective study of all deaths over a two-year period. In accordance with our institution's research ethics committee the exact years of study have been withheld. Since our interest is in the limits of medical, rather than surgical therapy, we have excluded from review cardiac and neonatal surgical intensive care patients. Mode of death has been classified as either failed cardiopulmonary resuscitation (CPR), brain death, terminal withdrawal of mechanical ventilation, or limitation of therapy with no escalation in inotropic or ventilatory support.

### Results

In the 24 consecutive months reviewed there were 89 children who died out of 651 admissions (13.7% mortality). Fifty-nine patients were admitted directly from another hospital to our PICU and the other 30 came from wards within the hospital. Their ages ranged from five days to 15 years (median 11 months) and the sex ratio was equal (45 girls, 44 boys). The median duration of admission was three days (interquartile range 2–5 days).

#### PREMORBID STATE AND REASON FOR ADMISSION

Thirty-three of the 89 patients (37%) were completely well before their illness necessitating intensive care, while six patients had an underlying condition first diagnosed during admission. Of the remaining 50 patients, 44 had a known underlying

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### Key words

Paediatric intensive care; withdrawal of support; futility; cardiopulmonary resuscitation; ethics.

Table 1 *Mode of death and premonitory state*

Mode of death	Total (%)	Normal	Undiagnosed disease	Underlying disease (lethal)	Recognised pattern of malformation
Failed CPR	16 (18)	4	1	8 (3)	3
Brain dead	15 (17)	11	0	4 (0)	0
Withdrawal	45 (50)	15	4	23 (1)	3
Limitation	13 (15)	3	1	9 (3)	0
	89 (100)	33	6	44 (7)	6

Table 2 *Mode of death in different series (%)*

	Present series	Salt Lake City <sup>a</sup>	Washington DC <sup>c</sup>	Chicago <sup>a</sup>	Alberta <sup>a</sup>	Lille <sup>e</sup>
Failed CPR	18	19	38	46	29	34
Brain dead	17	23	30	24	22	38
Withdrawal or limitation	65	58	32	30	49	28
Overall mortality	14	5	16	8	9	11

disease (including seven with lethal conditions) and six with a recognised pattern of malformation.

All of these children were admitted for mechanical ventilation. Twenty-six children had undergone CPR before admission. The three most frequent reasons for supportive therapy were: acute brain insult (48%), acute lung injury (26%), and sepsis syndrome or multiple organ system dysfunction (16%).

#### MODE OF DEATH

Sixteen children (18%) died after unsuccessful CPR on our unit. Another 15 children (17%) met criteria for brain death. Of the remaining 58 patients, 45 (50%) had mechanical ventilation withdrawn (including six children who had undergone the first set of brain death tests), and 13 children (15%) died whilst inotropic or ventilatory treatment was limited. The association between mode of death and premonitory state is shown in table 1.

In the 58 patients who either had their treatment limited or their mechanical ventilation withdrawn, the initial reason for supportive therapy was acute brain insult (40%), acute lung injury (21%), sepsis syndrome or multiple organ system dysfunction (24%) and others (mainly inherited disorders of metabolism) (15%). In 19 of these patients (33%), management had included use of a "do not resuscitate order" for cardiac arrest prior to the decision to limit or withdraw treatment.

## Discussion

In this review of 89 deaths occurring during paediatric medical intensive care only 18% resulted from failed emergency resuscitation. In two-thirds of the cases death occurred with a decision to limit medical treatment or withdraw mechanical ventilation, implying that additional or further therapy was considered futile. A comparison between this British experience and that described in similar North American and French paediatric medical series

(table 2), suggests that many physicians in the specialty believe that intensive care which offers no therapeutic potential should be discontinued.<sup>2-6</sup>

Our study has indicated that referral for intensive care during acute critical illness is not limited solely to children who were previously "normal". A significant proportion of the patients who died had underlying disease or malformations, which in some cases would be recognised as lethal conditions. One can only infer that in such instances, a decision to withdraw or limit treatment will be influenced by the expected increase in "total burden of disease" should the patient survive.

Acute critical illness in a child is often unexpected and the prospect of loss to the parents is profound.<sup>7</sup> Sadly, the futility of a given treatment such as mechanical ventilation may not become clear until after its initiation has raised inappropriate hope of long-term independent survival. We were therefore not surprised to find that death followed failed CPR in three patients with an underlying lethal condition who had been referred for intensive care. This presumably reflected failure to gain consent or parental agreement for a "do not resuscitate order". This is an unusual outcome when there has been sufficient time for the family to come to terms with all that has been discussed, which in our experience may take up to five days. Even so, there may be considerable emotional pressure to continue, rather than withdraw, futile therapy. These issues need to be recognised early and dealt with openly and compassionately.

In practice, as a child's clinical state worsens and the likelihood of a good outcome, or survival, lessens, the goals of medical management and appropriateness of new interventions need to be carefully considered. There is no legal obligation in the UK to subject a patient to a life-sustaining medical intervention when there is no expected long-term benefit.<sup>8</sup> Equally, if an extraordinary intervention is considered to be futile, there is no obligation to present it as an

option to the child's family.<sup>9</sup> Intensive care specialists are uniquely placed through their training, clinical expertise and interaction with the families concerned, to balance such clinical and ethical dilemmas. However, deciding whether continued survival in a seriously ill or debilitated state constitutes sufficient benefit is difficult and sometimes subjective. Critics suggest that it is impossible to make an objective medical judgment on futile treatment in many clinical situations as futility is not bound to a discrete and identifiable quantity, but instead encompasses a range of probabilities.<sup>10</sup> Furthermore futility is likely to be interpreted in different ways by different experts. In this context, we have not looked at the clinical process resulting in the decision to withdraw or limit life-sustaining therapies, but this will be necessary in the future. From our review it is apparent that such issues have become fundamental to the practice of paediatric intensive care.<sup>2-6</sup> For this reason, we believe that it is now time for the same rigorous approach taken in judging the effectiveness of one treatment over another to be applied to judging the appropriateness of giving any treatment at all. Comprehensive studies are needed to help clinicians derive consensus on what constitutes a futile intervention and when such an intervention should be withheld. This will help families and society understand that intensive care has its limits.

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### News and notes

## Consensus in Bioethics

A two-day national conference, Consensus in Bioethics: The search for Common Values in Our Approach to Bioethics, will be held at the University of Central Lancashire on the 17th and 18th of October this year.

The keynote address will be given by Alastair Campbell, currently Professor of Biomedical Ethics, University of Otago, New Zealand and Vice President

of the International Association of Bioethics. The organisers are the Centre for Professional Ethics, University of Central Lancashire.

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