Ethical dilemmas in critically ill children in Hong Kong

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Introduction

Paediatricians caring for critically ill children in an intensive care setting should be aware of the potential ethical issues and dilemmas that are unique to the paediatric population as it involves a triad of stakeholders—the patient, family, and healthcare professionals—all working towards the patient's best interest.[1] Being an international city under influences of both oriental and western cultures, Hong Kong's situation is unique and complex.

Ethical dilemmas

The four pillars of medical ethics—respect of autonomy, beneficence, non-maleficence and justice—were originally described in 1979 by Beauchamp and Childress,[2] and provide a clinical framework for decision making. In the United Kingdom, the Mental Capacity Act 2005[3] created a legal framework for decision making for adults lacking capacity. Capacity may fluctuate and must be carefully assessed. Capacity assessment must evaluate functional capacity, which is time- and decision-specific. When a person lacks capacity, a decision must be taken on their behalf that is in their best interests. In the paediatric intensive care unit (PICU), healthcare providers must be professional in communicating with parents, who may be under considerable emotional distress, and balance the wishes of the parents with the limited resources available to provide the optimal care for the patient.

Respect for autonomy

The concept autonomy refers to the integrity of a person's body, meaning that intervention or treatment cannot be carried out without the informed consent of the patient. Consent is a continuing process during a treatment plan and should be periodically reconfirmed. Nowadays, oncological emergencies form a major patient category in the PICU.[4,5] Some treatments may prolong suffering in patient with guarded prognosis. We encountered a case of parental autonomy that their consent to use eculizumab for the minor child, who is an immunocompromised patient, resulted in fatal disseminated fungal abscesses. The parents had been well informed of the potential fatal side-effects associated with the use of this drug.

In modern medicine, brain death is equivalent to cardiopulmonary death. The attending physicians are not obliged to treat a dead person.[6,7] However, parents or carers sometimes demand futile treatment for patients in the PICU.[8] A hospital ethics committee may help resolve such matters where the requested treatment may not be in the best interest of the patient. However, even members of an ethics committee may hold different opinions, making ethical decisions difficult. Cultural and religious beliefs are often important in ethical decisions involving brain death.[9] In some cultures, brain death may not be an accepted concept.[10] The matter is further confounded by possible organ donation implications. For example, in Japan, organs can be donated in legal brain death but not in general brain death.[11]

Beneficence and non-maleficence

'First do no harm' is a simple way of expressing the optimal balance between the potential benefits and harms of any treatment. In reality, physicians and caregivers may have different opinions about benefits and harms of treatment. We encountered a case of non-beneficence and maleficence that a ventilator-dependent infant on ketogenic diet for mitochondrial disease was given a high carbohydrate-containing nutrition product by the parents, which is contra-indicated in patient with mitochondrial disease.

Justice

Although least spoken about, the requirement for a just distribution of resources is a principle with political traction because it underpins rationing decisions in healthcare. In many countries with a public health service, it is accepted that people are treated according to their need rather than their ability to pay, but this arrangement is not universal. However, in situations where resources are limited, treatment of a brain dead child may result in the preclusion of allocating resources to another patient, leading to delay in treatment of that patient or even death.

Decision making and ethics consultation

Santoro et al[12] suggested that the decision-making processes in PICU are very complex and heterogenous with individual factors. Parents have an obligation to keep their children healthy and protected. However, when their child is exposed to life-altering changes, parents may be forced to consider a difficult balance between this protective role and the realistic outcome focusing on quality of life. Multiple personal and cultural factors affect parental decision making in ending the life support of their child.[13]

Ethics consultations are complex and might not be practical in the PICU setting. Divergent views on prognostic expectations and treatment goals are a frequent source of moral distress.[14,15]

Conclusion

Clinical ethical dilemma is becoming more common in our daily clinical practice, a clear and robust medical ethics framework to guide decision making in the PICU setting is required. Physicians and other healthcare workers in the PICU should consider a sensitive and thorough understanding of the interplay of the contributing factors in ethical dilemmas.

Author contributions

Concept or design: KL Hon.
Acquisition of data: KL Hon, KKY Leung.
Analysis or interpretation of data: KKY Leung, JCP Wong, P Ip.
Drafting of the manuscript: KL Hon, KKY Leung, JCP Wong.
Critical revision of the manuscript for important intellectual content: KL Hon, JCP Wong, P Ip, SY Qian.

All authors had full access to the data, contributed to the study, approved the final version for publication, and take responsibility for its accuracy and integrity.

Conflicts of interest

All authors have disclosed no conflicts of interest.

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