

## Emerging Priorities in Asian Paediatric Ethics

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Advances in medical care have resulted in a significant lowering of child mortality in Asia over the last three decades. However, perhaps paradoxically, increased availability of treatment and improving outcomes lead to more ethical dilemmas. Options generate choices, but the choices are not always easy. Rapid advances result in gaps in scientific knowledge (including the difficulty in applying knowledge obtained from other countries and other populations) and a consequent difficulty in deciding with a high level of certainty what would be in a child's best interests. The cost of newer treatments may outstrip the resources even of wealthy countries, leaving clinicians unsure whether to recommend expensive treatments, and parents facing enormous personal sacrifices and difficult dilemmas.

For children, in particular, there are tensions that arise from determining the appropriate decision-maker. In parts of Asia, medical paternalism is still widespread. Yet, there is rising awareness among both parents and young people of their right to participate in decision-making. This leads to the potential for conflicting views about treatment. It also means that societies and health systems need to decide whose views to prioritise when there is disagreement.

This Special Issue of the Asian Bioethics Review is dedicated to examining emerging ethical issues in contemporary paediatric practice, particularly exploring how these manifest and are addressed in an Asian context. The contributions were developed from papers presented at the inaugural Asian Paediatrics Ethics Conference held in Singapore in October 2023.

This issue opens with a Letter to the Editor from Erwin Khoo from Malaysia who reports on the inaugural work of the Bioethics Task Force of the Malaysian Paediatric Association [<https://link.springer.com/article/10.1007/s41649-024-00287-4>]. The account of this kind of body in supporting practitioners dealing with paediatric ethical dilemmas offers salient lessons about many of the issues that are explored in this issue.

Several papers explore cutting edge technologies and uncertainty. For example, Baral, Lim, Edison, and Menikoff from Singapore examine the ethical issues that arise when caring for newborns with severe hypoxic ischemic encephalopathy [<https://link.springer.com/article/10.1007/s41649-024-00337-x>]. In the last twenty years, therapeutic hypothermia has become a standard of care for such

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infants in high resource settings (though there remains scientific and ethical uncertainty about the appropriateness of this treatment in lower resource countries). After initial treatment, infants often enter a stage associated with high mortality and morbidity but with prognostic uncertainty. This raises questions about whether or when parents should have the option of withdrawal of life-sustaining treatment. Baral et al. emphasize the centrality of parents in the decision-making process and the importance of advocating for the child's interests while avoiding harm. They draw on US neonatologist Mark Mercurio's framework of Impermissible, Permissible and Obligatory Treatment (Mercurio and Cummings 2021) as a means to decide on proposed interventions in the light of stated and agreed upon treatment goals.

Similar questions about the boundaries of parental discretion in the setting of uncertainty are explored by Dominic Wilkinson and Julian Savulescu from Oxford and Singapore who debate choices of treatment at birth for extremely premature infants [<https://link.springer.com/article/10.1007/s41649-024-00299-0>]. They defend different views about when treatment would fall into Mercurio's "Permissible" category, though converge on some common ground relating to the option of adoption.

One of the ethical questions arising in that debate is the moral status of extremely immature newborn infants. That question is even more crucial in debates about treatment of fetuses. Jonathan Choo from Singapore in his paper on the ethics of foetal cardiac intervention addresses the unique situation of surgical intervention through the mother to treat the foetus [<https://link.springer.com/article/10.1007/s41649-024-00354-w>]. The rare and previously often fatal abnormality of foetal aortic stenosis can now be partially corrected through either in-utero aortic valvuloplasty and or inter atrial stenting. This enables the baby to survive long enough for post-natal repair. However, there are concomitant risks to the pregnancy and the mother. There are also logistical challenges in gaining sufficient experience to be able to offer this therapy safely. Choo's paper presents philosophical arguments that support the notion of the foetus as a patient and hence the development in the doctor of a duty to care. He then offers a framework that will enable an ethically justifiable approach to proposing foetal surgery.

A different source of uncertainty is explored by Yang, Son and Lee from South Korea [<https://link.springer.com/article/10.1007/s41649-024-00340-2>]. They take on the use of unproven interventions in seriously ill children. They point to the uniqueness of the developing child and propose categorizing unproven interventions based on the extent of research that has been done, determining if a public emergency exists, ensuring legal compliance, and presenting a clear delineation between the objectives of the intervention and research. In coming to a decision, they prioritise the child's best interests, well-being and rights, while giving respect to the parental role. They suggest that the danger of parents falling prey to a therapeutic misconception need to be averted by a robust informed consent process.

However, informed consent can be a considerable challenge. Mei Yoke Chan in her article observes that the major ethical issues in paediatric precision oncology in a Singaporean context arise from information overload and the overwhelming emotional turmoil that engulfs both the child and the parents

[<https://link.springer.com/article/10.1007/s41649-024-00351-z>]. This is compounded by therapeutic misconception, misestimation and the ambiguity between research and clinical care. All these contribute to making informed consent an elusive goal. She proposes that these could be mitigated through staged information delivery, and by having a dedicated team for securing consent and a whole-of-government approach to promote justice and equity.

Moving beyond formal 'consent', other papers in the special issue explore some of the unique issues arising from communication and decision-making for children in Asia. For example, Sarosh Saleem from Pakistan uses a case to illustrate the unique ethical obstacles in their socio-cultural and economic context faced by an IRB in implementing international guidelines related to the obtaining of assent from minors (i.e. the child's agreement to proceed, where the child is not of an age to provide informed consent) [<https://link.springer.com/article/10.1007/s41649-024-00342-0>]. The author proposes that stakeholders be more aware of these obstacles and suggest a reimagining of the assent process so that it becomes meaningful and mitigates potential risk to the children and adolescent research subjects.

On the other hand, Mora Claramita and Indah Kartika Muni from Indonesia highlight the dangers of accepting apparent parental endorsement and acceptance of information provided by professionals (which they label as "assent", though this is different from the child's assent in Saleem et al.'s paper) [<https://link.springer.com/article/10.1007/s41649-024-00355-9>]. They describe the communication challenges that exist in Asian cultures that have a strong non-verbal component in their communications. They propose the use of culturally sensitive and patient centred communication guides to improve communication and health outcomes.

Cultural and family sensitivity are important in two papers in the special issue that navigate family wishes in the setting of resource constraints. Sarah Abraham and Urmi Gosh from India draw on a number of cases to illustrate how in the face of severe resource constraints, courage and phronesis are required to deliver compassionate care that upholds the ethical principles of their health care institution [<https://link.springer.com/article/10.1007/s41649-024-00338-w>]. Hui Siu Tan from Malaysia explores four cases that have echoes of those from rural India. Tan illustrates some of the common challenges and the contribution of clinical ethics consultation when facing complex cases, especially those from migrant and refugee families [<https://link.springer.com/article/10.1007/s41649-024-00339-9>].

Finally, Daniel Tsai and Yu-Chen Chou from Taiwan provide an ethical reflection on "children's autonomy" from the perspective of cross-cultural bioethics and based on theories related to so-called Asian values (i.e. those that are thought to be particularly prevalent, distinctive or important in an Asian context) [<https://link.springer.com/article/10.1007/s41649-024-00358-0>]. They support the premise of "children's autonomy" and explore the differences between Western and non-Western cultures regarding claims of children's autonomy. They describe how Tsai's own two-dimensional personhood theory can be used to balance the tension between individual autonomy, family determinism, children's autonomy and paternalism. They propose that this framework can

provide a rational resolution to the long standing cross-cultural bioethical controversy regarding individual autonomy and family determinism.

This collection of papers provides a snapshot of emerging challenges in paediatric ethics in Asia. While many of these ethical questions overlap with those that are prevalent in paediatrics in other parts of the world, the papers identify distinctive manifestations of ethical problems. That includes the locally specific interpretation of common ethical frameworks (for example 'Permissible' parental choices), contextual factors that influence the navigation of novel health technologies (e.g. foetal intervention, oncology therapies), and some of the unique cultural challenges in communication and shared decision-making in Asia.

## **References**

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[Editorial]

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**Advancing Bioethical Standards: Charting the Course of the Inaugural Malaysian Paediatric Association Bioethics Task Force**

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**Ethical considerations in newborn infants with Hypoxic Ischemic Encephalopathy**

Vijay R. Baral, Yinru Lim, Priyantha Edison, and Jerry Alan Menikoff

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**Debate: Should Parents Should Be Able to Request Non-Resuscitation for All Extremely Premature Newborn Infants?**

Dominic Wilkinson and Julian Savulescu

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**The Ethics of Fetal Cardiac Intervention**

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**Hoping against hope: Ethical considerations when trying unproven treatment for seriously ill children**

Ji Hyun Yang, Yumi Son, and Ilhak Lee

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**Ethical Issues in Pediatric Precision Oncology in Singapore**

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**Reimagining Assent: When things get lost in translation in International Pediatric Research**

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**The complexity of an agreement: a cross-cultural perspective on "yes, doctor" communication with patient**

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**Displaying moral courage in providing discretionary treatment in a technologically advanced, yet resource limited setting**

Sarah Abraham and Urmi Gosh

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**What's Best and Who Decides for Seriously Ill Infant? A Malaysian Perspective**

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**Some Asian Value Reflections on Children's Autonomy**

Daniel Fu-Chang Tsai and Yu-Chen Chou