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van Zuuren, F. J., and E. van Manen. 2006. Moral dilemmas in neonatology as experienced by health care practitioners: A qualitative approach. Medicine, Health Care, and Philosophy 9 (3):339-47. doi:10.1007/s11019-005-5641-6.

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Respect Without Romanticizing: Cultural Values, Parental Reasons, and Unproven Pediatric Treatments in East Asia

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INTRODUCTION

Moore and Caruso Brown (2025) offer a compelling framework for understanding the ethical significance of parental reasons in pediatric decision-making. Their taxonomy, including not only pragmatic perspectives but also epistemic, social-cognitive, and value-based arguments, clarifies that parental reasoning is not a peripheral consideration but a central component of ethical judgments.

Building on this insight, this commentary advances the discussion of the ethics of parental reasoning, focusing on situations in which unproven pediatric treatments (UPTs) are sought for critically ill children. In such contexts, drawing a clear ethical boundary between acceptable and unacceptable parental reasoning is essential.

To illustrate this argument, we examine two prominent case studies: Hwang Woo-suk's stem cell scandal in South Korea and the controversy over the use of umbilical cord blood in Japan. Both cases reveal how excessive expectations for novel treatments, often shaped by social norms regarding parental obligations, can fuel therapeutic misconception and lead to the exploitation of parental sacrifice in research and

clinical settings. These examples underscore the need for careful and context-sensitive evaluation of parental reasoning in medical decision-making.

CASE STUDY 1: THE HWANG WOO-SUK SCANDAL IN SOUTH KOREA

The Hwang Woo-suk scandal, involving fabricated stem cell research, became one of the most high-profile cases of research misconduct in Korea. An overlooked aspect of this affair is that Hwang's fabricated findings supported a proposed clinical trial for a 12-year-old boy with paralysis due to his spinal cord injury. According to media reports, the boy donated his somatic cells, his mother donated her eggs, and his father was an IRB committee member approving the study. Thus, the entire family became research participants and collaborators, united by the shared hope for a cure (Hong 2005; Yang 2005).

For parents of disabled children, such a hope was not simply aspirational—it carried a moral obligation to pursue even the slightest possibility of restoring their child's health (Yang, Son, and Lee 2025). The boy's father publicly prioritized grace and national

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pride over procedural misconduct even after the fraud was exposed. Simultaneously, the mother's contribution embodied maternal devotion in line with cultural and religious ideals (Tsuge and Hong 2011). However, their commitment to family and science was used to bolster the credibility of Hwang's research. This illustrates how sincere parental reasoning can be exploited by institutional actors, especially when scientific uncertainties are obscured by moral rhetoric.

From Moore and Caruso Brown's framework, the parents' decision was epistemically undermined by misinformation created through Hwang's deceptive practices and inappropriate media coverage. However, the interviews and case analyses suggest the parents were fully aware of community expectations about parental duties and family-oriented decision-making. Such sociocultural beliefs, when genuinely held, warrant serious ethical consideration.

Moreover, when cultural practices, such as parental devotion and a family-centered conception of autonomy (Yung 2015), convey moral values specific to a society, parental decisions grounded in these values may possess intrinsic ethical relevance. This is particularly evident in the mother's donation, motivated by the Korean value of jeong (情), representing profound emotional bonds and unwavering family devotion (Oh 2022).

A third factor—the risk of socio-cognitive biases on the side of experts-might be less directly relevant here, as the case unfolded primarily within basic scientific research. However, the parents' cooperation and hope may have amplified the researchers' bias, not undermining but exploiting their reasoning, thereby rendering the family vulnerable to misconduct.

CASE STUDY 2: THE UMBILICAL CORD BLOOD **CONTROVERSY IN JAPAN**

Japan offers a similar controversy in which parents' genuine hope for their children's well-being risks exploitation by medical professionals and commercial entities. In Japan, public umbilical cord blood (UCB) banks, regulated under the Act Regarding the Promotion of the Appropriate Supply of Hematopoietic Stem Cells for Transplant (2014; last amended 2025), store and distribute donated UCB for established clinical uses, such as transplantation in patients with blood diseases like leukemia.

However, until recently, private UCB banks operated largely without regulation, and they collected and stored UCB for various purposes, including off-label use for donors or their children. A 2017 national survey revealed that over one third of childbirth institutions supplied UCB to private banks, often without adequate explanation or informed consent (Murata et al. 2022). The same year, physicians and a vendor were convicted for illegally administering UCB purchased from a bankrupt private bank, which had stored donated units beyond the contracted period (Ibid., 4-5). This scandal led to a 2019 legal amendment that effectively banned nearly all private UCB transactions, with few exceptions.

Parents may reasonably donate and store UCB to secure their child's future source of HLA-compatible stem cells. Yet such concern can be distorted by unfounded hopes for unproven clinical applications such as treating autism or cerebral palsy-promoted by clinics and influencers. Notably, in 2018, the parents of a boy with cerebral palsy launched an advocacy group for UCB therapy (Higa 2018), well after the scandal became public.

While this controversy does not involve clear research misconduct like Hwang's case, Moore and Brown's framework remains Epistemically, the Japanese parents, similar to the Korean parents, may have had a limited understanding of scientific reality, shaped by misleading media coverage. However, they were also aware of their cultural expectations: limitless care for critically ill children, and the akiramenai (諦めない, meaning "fight to the very last") attitude even in the least hopeful situations. If such devotion is morally valuable—just like jeong in the Korean context—their parental reasoning in favor of UCB donation may also hold prima facie ethical significance.

Here, too, the greater problem lies in expert bias toward parental reasons. Even if no severe health damage has been reported from self-funded, off-label UCB transplants thus far (setting aside the parents' financial loss for an unnecessary UPT), the risk remains as long as clinics withhold relevant scientific facts and raise unrealistic expectations. In such cases, parental reasoning is not simply flawed; it is actively exploited for the benefit of experts.

IMPLICATIONS AND ETHICAL RESPONSIBILITY **IN UPTS**

These cases illustrate that appeals to "respect for parental reasons" in UPTs can make families vulnerable to exploitation. Misinformation can distort such reasoning; without Hwang's fabrication and misleading media, the parents likely would not have pursued those UPTs. Faced with a child's serious illness, parents understandably grasp at slim options despite scant evidence. But this pressure warrants asking whether undue influence has compromised their reasoning. This raises the question of whether the decision reflects authentic choice or manipulated reasoning. This reflects the principle that manipulation can undermine the validity of purported "informed" consent (Beauchamp and Childress 2019).

Importantly, this is not only about blaming experts. In Korea, parents—particularly mothers—face scrutiny from extended families and peers, and bear disproportionate moral responsibility for their children's health. In Japan, families may feel bound by obligations to fulfill generational roles, which can lead to treatment choices reflecting the preferences of elder family members rather than the patient's. Such situations are common: some represent benign instances of shared decision-making that reflect East Asian values, while others constitute undue manipulation that is as ethically problematic as professional misconduct. In either case, these cultural dynamics significantly shape how parental reasons are formed, expressed, and interpreted.

As Moore and Caruso Brown observe, their framework does not require unconditional deference to parents (Moore and Caruso Brown 2025). Instead, it provides a theoretical tool for examining when, how, and why parental reasons carry ethical weight. In East Asian contexts, applying this requires serious engagement with culturally specific ways of reasoning, while remaining alert to the risk of undue manipulation. The task, therefore, is to ensure that proposed treatments are supported by credible scientific and clinical evidence, and that such information is communicated appropriately to patients and their family members; to critically examine the cultural expectations that inform a family's sense of obligation and the ways these shape decision-making; and to consider what it means to respect a family's values without affirming every decision made in their name. In some circumstances, honoring jeong or akiramenai attitude may mean enabling a safe and dignified withdrawal from treatment, rather than pushing forward out of guilt or fear.

Ethical deliberation in UPT cases must go beyond calculating risk-benefit ratios. It must also engage with the moral goods-hope, love, and identity-that make parental reasons powerful in the first place. Epistemically, clinicians should ensure that parents are not operating under a therapeutic misconception or misplaced optimism. Socio-cognitively, they must recognize how cultural norms and role expectations can silence doubt and reinforce compliance. Finally, regarding moral values, they must remain sensitive to how deeply rooted virtues, such as jeong or akiramenai, can engender moral vulnerability. As Moore and Caruso Brown rightly emphasize, leaving parental reasons implicit in the background can diminish their ethical significance. The challenge, then, is to respect them without romanticizing them, to analyze them without dismissing them, and to protect them from becoming what they were never meant to be: tools for others' gain.

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REFERENCES

Beauchamp, T. L., and J. F. Childress. 2019. Principles of biomedical ethics. 8th ed. New York: Oxford University Press. Higa, M. 2018. 脳性まひ患う息子を救いたい 臍帯血移植 の実現目指し、沖縄で団体発足 [Save our son with cerebral palsy: Group launched in Okinawa to advocate for UCB transplantation]. Okinawa Times, August 16. Accessed August 12, 2025. https://www.okinawatimes.co. jp/articles/-/299353.

Hong, H.-J. 2005. "줄기세포 하나만 믿고 버텼는데..." ["I held on, believing only in stem cells ..."]. KBS News. December 23. Accessed August 12, 2025. https://news. kbs.co.kr/news/pc/view/view.do?ncd=815059.

Moore, B., and A. Caruso Brown. 2025. Do reasons matter? Navigating parents' reasons in healthcare decisions for children. The American Journal of Bioethics 25 (11):6-21. doi:10.1080/15265161.2024.2388730.

Murata, M., K. Kawabe, T. Hatta, S. Maeda, and M. Fujita. 2022. Current status of umbilical cord blood storage and provision to private biobanks by institutions handling childbirth in Japan. BMC Medical Ethics 23 (1):92. doi:10.1186/s12910-022-00830-8.



Oh, J. S. 2022. Emotions (Jeong 情) in Korean Confucianism and family experience: An ecofeminist perspective. In Emotions in Korean philosophy and religion: Confucian, comparative, and contemporary perspectives, ed. E. Y. J. Chung, and J. S. Oh, 315–334. Cham: Springer. doi:10.1007/978-3-030-94747-7_12.

Tsuge, A., and H. Hong. 2011. Reconsidering ethical issues about "voluntary egg donors" in Hwang's case in global context. New Genetics and Society 30 (3):241-52. doi:10.1 080/14636778.2011.598053.

Yang, J. H., Y. Son, and I. Lee. 2025. Hoping against hope: Ethical considerations when trying unproven treatments for seriously ill children. Asian Bioethics Review 17 (2):279-91. doi:10.1007/s41649-024-00340-2.

Yang, M.-H. 2005. 수의대 IRB, 황 교수팀이 직접 짰다 [The veterinary school's IRB was directly established by Professor Hwang's team]. KBS News, December 23. Accessed Aug 12, 2025. https://news.kbs.co.kr/news/pc/ view/view.do?ncd=815035.

Yung, L. Y. Y. 2015. The East Asian family-oriented principle and the concept of autonomy. In Family-oriented informed consent, ed. R. Fan, 107-121. doi:10.1007/978-3-319-12120-8_7. Cham: Springer.

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Relational Reasons and Moral Worth: A Southeast Asian Perspective on Parental Justification in Pediatric Ethics

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This commentary responds to Moore and Caruso Brown's (2025) article, "Do Reasons Matter? Navigating Parents' Reasons in Healthcare Decisions for Children," offering a Southeast Asian perspective on how parents justify healthcare decisions for their children. The original article rightly calls for clinicians to look beyond outcomes and consider the moral weight of the reasons parents give. While their analysis is grounded in liberal ethical theory, I extend this discussion by highlighting alternative understandings of decision-making-particularly those that are relational rather than purely individual.

In Southeast Asia, particularly in Malaysia, a multicultural society, moral reasoning rarely fits neatly into practical, epistemic, and ethical categories. Cultural values, religious beliefs, and social expectations often overlap, shaping how reasons are formed, interpreted, and weighed. Parental decisions are not just about individual autonomy, but more about fulfilling obligations within families and

communities. This is not to suggest that pediatric patients lack autonomy or that their voices are unimportant. Indeed, the autonomy of children should be respected. But in many cases, children are either not given or considered not ready to exercise their autonomy, making parental reasoning all the more important. While these tensions are real, the focus of this commentary is to examine the moral significance of parental reasons through a culturally grounded lens.

Relational autonomy, which sees moral agency as shaped by social roles, obligations, and interdependence, provides a culturally relevant way to understand how parents make these decisions. In Malaysia, for example, decisions around a child's care often reflect a broader sense of responsibility to maintain family unity, fulfill religious duties, or preserve social harmony. While Western ethics might classify certain parental influences as undue influence or coercion, in Southeast Asian context, such action may at times